## REPORT OF THE VIRGINIA COMMISSION ON YOUTH

## Collection of Evidence-based Practices for Children and Adolescents with Mental Health Treatment Needs, 6<sup>th</sup> Edition

## TO THE GOVERNOR AND THE GENERAL ASSEMBLY OF VIRGINIA



### **SENATE DOCUMENT NO. 6**

COMMONWEALTH OF VIRGINIA RICHMOND 2017



#### COMMONWEALTH of VIRGINIA

Commission on Youth

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December 28, 2017

Dear Fellow Citizen of the Commonwealth:

It is my pleasure as Chair of the General Assembly's Commission on Youth to present the 6<sup>th</sup> Edition of the *Collection of Evidence-based Practices for Children and Adolescents with Mental Health Treatment Needs.* The *Collection* summarizes current research on those mental health treatments that have been proven to be effective in treating children and adolescents. The *Collection* is intended to serve a broad readership, including educators, service providers, parents, caregivers, and others seeking information on evidence-based mental health practices for youth.

Section 30-174 of the *Code of Virginia* establishes the Virginia Commission on Youth and directs the Commission to "study and provide recommendations addressing the needs of and services to the Commonwealth's youth and their families." This section also directs the Commission to "encourage the development of uniform policies and services to youth across the Commonwealth and provide a forum for continuing review and study of such services."

The 2002 General Assembly, through Senate Joint Resolution 99, directed the Virginia Commission on Youth to coordinate the collection of empirically-based information to identify the treatments that are recognized as effective for children, including juvenile offenders, who have mental health treatment needs, symptoms, and disorders. The resulting publication entitled *Collection of Evidence-based Practices for Children and Adolescents with Mental Health Treatment Needs* was compiled by the Commission with the assistance of an advisory group of experts pursuant to Senate Joint Resolution 99. The *Collection* was published in House Document 9 and presented to the Governor and the 2003 General Assembly.

To ensure that this information remained current and reached the intended audience, the 2003 General Assembly passed Senate Joint Resolution 358, which requires the Commission on Youth to update the *Collection* biennially. The resolution also requires the Commission to disseminate the *Collection* via web technologies. The Secretaries of Health and Human Resources, Public Safety and Education, along with the Advisory Group, were requested to assist the Commission in updating the *Collection*, as were various state and local agencies. Since 2003, the Commission has updated this resource and made it available through the Commission on Youth website and in print editions.

The Commission on Youth gratefully acknowledges the contributions of its Advisory Group members. For more information about the Virginia Commission on Youth or the *Collection*, I encourage you to visit our website at <a href="http://vcoy.virginia.gov">http://vcoy.virginia.gov</a>.

Sincerely,

Barbara A. Favola

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#### DISCLOSURE STATEMENT

The information contained herein is strictly for informational and educational purposes only and is not designed to replace the advice and counsel of a physician, mental health provider, or other medical professional. If you require such advice or counsel, you should seek the services of a licensed mental health provider, physician, or other medical professional. The Commission on Youth is not rendering professional advice and makes no representations regarding the suitability of the information contained herein for any purpose.

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## NTRODUCTION

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#### **Background of Child and Adolescent Mental Health**

The recognition that children and adolescents suffer from mental health disorders is a relatively recent development. Throughout history, childhood was considered a happy period. It was believed that because children were spared the stressors that afflict adults, they did not suffer from true mental disorders (American Psychiatric Association [APA], 2002). It is now well-recognized that mental or emotional distress in youth may not just be a stage of childhood or adolescence, but can be evidence of a mental disorder caused by genetic, developmental, and physiological factors.

Although research conducted in the 1960s revealed that children do suffer from mental disorders (APA, 2002), it was not until 1980, when the third edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-III)* was published by the APA, that child and adolescent mental disorders were assigned a separate and distinct section within the classification system (National Institute of Mental Health [NIMH], 2001). The development of treatments, services, and methods for preventing mental health disorders in children and adolescents has continued to evolve over the past several decades.

The National Alliance for the Mentally III (NAMI) defines mental illness as a disorder of the brain that may disrupt a person's thinking, feeling, moods, and ability to relate to others (2005). In 2013, the APA released the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*). Significant changes were made to the criteria and categories of mental disorders and these changes are discussed in detail throughout this *Collection*. The definition of a mental disorder was also modified in the *DSM-5* as follows:

A mental disorder is a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental

disorders are usually associated with significant distress in social, occupational, or other important activities. An expectable or culturally approved response to a common stressor or loss, such as the death of a loved one, is not a mental disorder. Socially deviant behavior (e.g., political, religious, or sexual) and conflicts that are primarily between the individual and society are not mental disorders unless the deviance or conflict results from a dysfunction in the individual, as described above (APA, 2013).

In early December 1999, U.S. Surgeon General David Satcher released the first ever Surgeon General's report on Mental Health. This report called attention to the seriousness of mental illness as an "urgent health concern" (U.S. Department of Health and Human Services, 1999). The report also discussed the needs of specific populations such as children and provided the first comprehensive, nationwide, longitudinal data on the development of children's mental health. This report noted that mental health disorders appear in families of all social classes and backgrounds. However, some children are at greater risk due to other factors. These factors include physical problems, intellectual disability, low birth weight, family history of mental and addictive disorders, multigenerational poverty, and caregiver separation or abuse and neglect (U.S. Department of Health and Human Services). Risk factors and causal influences for mental health disorders in youth vary, depending on the specific disorder.

Child and adolescent mental health has emerged as a distinct arena for service delivery. With the increased attention given to children's mental health and the development of systems of care for children with serious emotional disorders and their families, mental health has emerged as a new focus in the field of early childhood (Woodruff et al.). Family members, practitioners, and researchers have become increasingly aware that mental health services are an important and necessary support for youth who experience mental, emotional, or behavioral challenges and their families.

#### **Epidemiology and Burden of Child and Adolescent Mental Health Problems**

According to the New Freedom Commission on Mental Health established by President George W. Bush, childhood is a critical period for the onset of behavioral and emotional disorders (2003). Between 13 to 20 percent of children living in the United States experience a mental disorder in a given year (Centers for Disease Control and Prevention [CDC], 2013). Researchers supported by the National Institute of Mental Health (NIMH) found that half of all lifelong cases of mental health disorders begin by age 14 (Archives of General Psychiatry, as cited by the NIMH, 2005). Moreover, there are frequently long delays between the first onset of symptoms and the point at which people seek and receive treatment. This study also noted that a mental health disorder left untreated could lead to a more severe, more difficult-to-treat illness and to the development of co-occurring mental health disorders. In addition, nearly half of all individuals with one mental disorder met the criteria for two or more disorders (NIMH).

The National Comorbidity Survey Replication Adolescent Supplement (NCS-A) is a nationally representative face-to-face survey of 10,123 adolescents aged 13 to 18 years in the United States. Conducted between 2001 and 2004, the survey was designed to estimate the lifetime prevalence, age-of-onset distributions, course, and comorbidity of mental health disorders among children and adolescents. NCS-A found the overall prevalence of youth with mental health disorders with severe impairment and/or distress to be 22 percent (Merikangas et al., 2010). Study results

revealed that anxiety disorders were the most common condition, followed by behavior disorders, mood disorders, and substance use disorders, with approximately 40 percent of those with one class of disorder also meeting criteria for another class of lifetime disorder (Merikangas et al.).

There has been little research to measure the financial burden of mental health disorders in children and adolescents. However, a team of researchers analyzed various data sources to locate information on the utilization and costs associated with mental health disorders in youth. They estimated that the cost of mental disorders among persons younger than 24 years of age in the United States was \$247 billion annually (CDC, 2013). This includes costs associated with health care, special education, juvenile justice, and decreased productivity. Mental disorders were among the most costly conditions to treat in children (CDC). This analysis, along with other studies, pointed to two reasons why national health expenditures for child and adolescent mental disorders are difficult to estimate, including:

- Mental health services are delivered and paid for in the health, mental health, education, child welfare, and juvenile justice systems; and
- No comprehensive national datasets exist in this area (CDC; Sturm et al. 2001; Ringel & Sturm, 2001).

Child and adolescent preventive interventions have the potential to significantly reduce the economic burden of mental health disorders by reducing the need for mental health and related services. Furthermore, such interventions can improve school readiness, health status, and academic achievement and reduce the need for special education services (National Institute for Health Care Management, 2005). These interventions also translate into societal savings by lessening parents' dependence on welfare and increasing educational attainment and economic productivity (National Institute for Health Care Management).

#### Serious Emotional Disturbance

Serious emotional disturbance (SED) refers to a diagnosable mental health problem that severely disrupts a youth's ability to function socially, academically, and emotionally. While SED is defined by federal regulation, states may provide additional guidance to professionals (Substance Abuse and Mental Health Services Administration [SAMHSA], 2016). Virginia's Department of Behavioral Health and Developmental Services (VDBHDS) outlines the following as criteria for SED:

- 1. Problems in personality development and social functioning that have been exhibited over at least one year's time;
- 2. Problems that are significantly disabling, based on the social functioning of most children of the child's age;
- 3. Problems that have become more disabling over time; and
- 4. Service needs require significant intervention by more than one agency (VDBHDS, 2013).

Estimates of the number of children suffering from SED vary significantly depending on the study cited. One study attempting to collect SED prevalence rates found that variations in

estimates for SED might be explained due to the varying objectives for collecting the data as well as the types of methodology used for selecting the study populations. A follow up literature review of this study effort found that national SED estimates range from five to 26 percent (Brauner & Stephens, 2006). According to prior research, about one out of every ten youths with a current mental disorder fulfill criteria for SED based on the Substance Abuse and Mental Health Services Administration (SAMHSA) definition (i.e., a mental health problem that has a drastic impact on a child's ability to function socially, academically, and emotionally) (Merikangas et al., 2010).

A recent study conducted by the Federal Interagency Forum on Child and Family Statistics (2015) found that the percentage of children with SED was about five percent in most years between 2001 and 2013 (2015). Among children with SED, 23 percent received special education services for an emotional or behavioral problem, 43 percent had a parent who had contacted a general doctor about the child's emotional or behavioral problem, and 55 percent had a parent who had contacted a mental health professional about the child (Federal Interagency Forum on Child and Family Statistics). In Virginia, it is estimated that between 117,592 and 143,724 children and adolescents have a SED, with between 65,329 and 91,461 exhibiting extreme impairment (VDBHDS, 2013).

#### **Providing Optimal Treatment**

The acknowledgment of mental health needs in youth has prompted further study on a variety of disorders and their causes, prevention, and treatments. Child and adolescent mental health represents a major federal public health priority, as reflected in the U.S. Surgeon General's *Report of the Surgeon General's Conference on Children's Mental Health: A National Action Agenda* (2000). The report outlines the following three steps that must be taken to improve services for children with mental health needs:

- Improving early recognition and appropriate identification of disorders within all systems serving children;
- Improving access to services by removing barriers faced by families; and
- Closing the gap between research and practice to ensure evidence-based treatments for children.

Without appropriate treatment, childhood mental health disorders can escalate. Untreated childhood mental health disorders may also be precursors of school failure, involvement in the juvenile justice system, and/or placement outside of the home. Other serious outcomes include destructive, ambiguous, or dangerous behaviors, in addition to mounting parental frustration. The resulting cost to society is high in both human and financial terms. Identifying a child's mental health disorder early and ensuring that the child receives appropriate care can break the cycle (New Freedom Commission on Mental Health, 2003).

#### Identifying and Encouraging the Use of Evidence-based Treatments

There have been more than two decades of research in treating child and adolescent mental health disorders. However, there are challenges to helping families and clinicians select the best treatments. The field of child and adolescent mental health is multi-disciplinary, with a diverse

service system. Today, there are a multitude of theories about which treatments work best, making it is very difficult for service providers to make informed choices.

Scientific evidence can serve as a guide for families, clinicians, and other mental health decision-makers. Interventions that have strong empirical support are referred to as empirically validated treatments, empirically supported treatments, evidence-based treatments, or evidence-based practices. All of these terms attempt to capture the notion that the treatment or practice has been tested and that its effects have been demonstrated scientifically.

#### Benefits of Evidence-Based Treatments

Evidence-based medicine evolved out of the understanding that decisions about the care of individual patients should involve the conscientious and judicious use of current best evidence (Fonagy, 2000). Evidence-based treatments allow patients, clinicians, and families to see the differences between alternative treatment decisions and to ascertain what treatment approach best facilitates successful outcomes (Donald, 2002). Treatments that are evidence-based and research-driven complement a clinician's experience in practice. Evidence-based medicine has significantly aided clinicians in the decision-making process by providing a fair, scientifically rigorous method of evaluating treatment options.

Evidence-based medicine also helps professional bodies develop clearer and more concise working practices and establish treatment guidelines. The accumulated data for evidence-based treatments support their consideration as first-line treatment options (Nock, Goldman, Wang, & Albano, 2004). With literally hundreds of treatment approaches available for some disorders, it is difficult for clinicians to select the most appropriate and effective intervention (Nock et al.). The strongest argument in support of using evidence-based practices is that they enable clinicians to identify the best-evaluated methods of health care. Evidence-based treatments are recognized as an important component in behavioral health care by professional organizations, and increasingly, insurance companies and other payers are reluctant to pay for services without an evidence base (Society of Clinical Child & Adolescent Psychology, 2012).

Another driving force in the utilization of evidence-based medicine is the potential for cost savings (Fonagy, 2000). With rising awareness of mental health issues and a demand by consumers to obtain the best treatment for the best price, the emphasis on evidence-based practices is both practical and justified. Few people have time to conduct research in order to evaluate best practices. Evidence-based medicine provides a structured process for clinicians and patients to access information on what is effective. Moreover, studies have shown that evidence-based practices work in a relatively short time span and lead to long-standing improvements.

#### Limitations of Evidence-Based Treatments

There are stakeholders in the field of children's mental health who have regarded the evidence-based treatment movement with skepticism. According to Michael Southam-Gerow, Assistant Professor of Clinical Psychology and Director, Graduate Studies at the Department of Psychology at Virginia Commonwealth University, there are several criticisms surrounding the utilization of evidence-based treatments (Personal Communication, December 15, 2009). These include the following:

- There is too much information, making it difficult for a service provider to choose a treatment among many that may be supported for a particular problem.
- There is too little information and there are distinct problem areas for which there is still very little known.
- The evidence is inadequate and it has been argued that there is insufficient supportive data to favor one treatment versus another. Furthermore, the long-term effects of many treatments are unknown. More studies are needed before treatments are categorized as being evidence-based.
- Because a treatment has not been tested does not mean it is not effective. Some
  commonly used treatments are not deemed to be evidence-based treatments because they
  have not been tested.

Additionally, evidence-based practices as currently developed and implemented may have inherent limitations that prevent their widespread delivery (Kazdin, 2011). Many of the evidence-based practices cannot reach individuals at the scale needed, particularly if they are provided on a one-to-one, in-person basis. There are challenges in extending evidence-based practices to patient care on a scale sufficient to have impact on the personal and social burdens of mental illness. As noted previously, many mental health disorders do not yet have an accompanying evidence-based practice. While there are limitations in the development and implementation of evidence-based practices, a number of these practices are effective across a range of disorders, suggesting some common mechanisms or core processes (U.S. Department of Health & Human Services, 2015).

#### Background of the Collection

The 2002 General Assembly, through Senate Joint Resolution 99, directed the Virginia Commission on Youth to coordinate the collection of treatments recognized as effective for children and adolescents, including juvenile offenders, with mental health disorders. The resulting publication, the *Collection of Evidence-based Practices for Children and Adolescents with Mental Health Treatment Needs (Collection)* was compiled by the Commission on Youth with the assistance of an advisory group of experts.

In 2003, the General Assembly passed Senate Joint Resolution 358, requiring the Commission to update the *Collection* biennially. The resolution also required the Commission to disseminate the *Collection* via web technologies. As specified in this resolution, the Commission received assistance disseminating the *Collection* from the Advisory Group and other impacted agencies. The *Collection* has been updated five times since 2002.

In 2013, the American Psychiatric Association made several significant changes to the categorization of disorders included in the *Diagnostic and Statistical Manual Fifth Edition* (*DSM-5*). The Commission has made significant revisions to the *Collection* 6<sup>th</sup> *Edition* to incorporate these changes.

#### Using the Collection 6th Edition

With the limitations of evidence-based treatments in mind, the *Collection* 6<sup>th</sup> *Edition* has been updated to reflect the current state of the science. It has been developed and updated to provide information to families, clinicians, administrators, policymakers and others seeking information about evidence-based practices for child and adolescent mental health disorders. The *Collection* 6th Edition has four categories that represent different levels of scientific support for a particular treatment. These levels are summarized in Table 1. Because research is ongoing, treatments are expected to move around among the categories with time.

The *Collection* 6<sup>th</sup> *Edition* also includes information on assessment instruments. This is to emphasize that all clinical decisions should be made in consultation with the data. Patient data should be collected to justify treatment plans, changes in treatment plans, and terminations. Clinicians and mental health treatment organizations are becoming both data-driven and data collectors, allowing for greater opportunities for outcome measures to be collected and reviewed during the course of treatment.

#### Conclusion

Effective mental health treatments that have undergone testing in both controlled research trials and real-world settings are available for a wide range of diagnosed mental health disorders. The *Collection*  $6^{th}$  *Edition* is designed to encourage use of these treatments by professionals providing mental health treatments. The *Collection*  $6^{th}$  *Edition* is also designed to provide parents, caregivers, and other stakeholders with general information about the various disorders and problems affecting children and adolescents.

Evidence-based treatments have been developed with the express purpose of improving the treatment of child and adolescent mental health disorders (Nock et al., 2004). Clinicians can incorporate these well-documented treatments, while still adequately addressing the individual differences of the patient (Nock et al.).

Table 1
Treatment Categories Used in Collection 6<sup>th</sup> Edition

Levels of Scientific Support	Description	
What Works (Evidence-based Treatment)	<ol> <li>Meets all of the following criteria:</li> <li>Tested across two or more randomized controlled trials (RCTs);</li> <li>At least two different investigators (i.e., researcher);</li> <li>Use of a treatment manual in the case of psychological treatments; and</li> <li>At least one study demonstrates that the treatment is superior to an active treatment or placebo (i.e., not just studies comparing the treatment to a waitlist).</li> </ol>	
What Seems to Work	Meets all but one of the criteria for "What Works" or Is commonly accepted as a valid practice supported by substantial evidence	
What Does Not Work	Meets none of the criteria above but meets either of the following criteria:  1. Found to be inferior to another treatment in an RCT; and/or  2. Demonstrated to cause harm in a clinical study.	
Not Adequately Tested	Meets none of the criteria for any of the above categories. It is possible that such treatments have demonstrated some effectiveness in non-RCT studies, but their potency compared to other treatments is unknown. It is also possible that these treatments were tested and tried with another treatment. These treatments may be helpful, but would not be currently recommended as a first-line treatment.	

#### **Resources and Organizations**

#### **American Academy of Family Physicians**

https://www.aafp.org

#### American Association of Child & Adolescent Psychiatry (AACAP)

http://www.aacap.org/

#### **American Psychiatric Association (APA)**

http://www.psych.org

http://www.parentsmedguide.org

#### **American Psychological Association (APA)**

http://www.apa.org/

#### Familydoctor.org

https://familydoctor.org/

#### **Medscape Today Resource Centers (from WebMD)**

https://www.medscape.com/internalmedicine

#### **National Alliance for the Mentally III (NAMI)**

https://www.nami.org/

#### **National Institute of Mental Health (NIMH)**

http://www.nimh.nih.gov/index.shtml

#### **National Registry of Evidence-based Programs and Practices**

http://www.nrepp.samhsa.gov

#### National Technical Assistance Center for Children's Mental Health

https://gucchdtacenter.georgetown.edu/

#### **Substance Abuse and Mental Health Services Administration (SAMHSA)**

Caring for Every Child's Mental Health Campaign

http://www.samhsa.gov/children

#### **U.S. Department of Education**

Office of Special Education and Rehabilitative Services

https://www2.ed.gov/about/offices/list/osers/index.html?src=mr

#### U.S. Department of Health and Human Services

Centers for Disease Control and Prevention (CDC)

https://www.cdc.gov/

## U.S. National Library of Medicine and the National Institutes of Health (NIH) Medline Plus

https://medlineplus.gov/

#### **Virginia Resources and Organizations**

#### 1 in 5 Kids Campaign

https://vakids.org/our-work/mental-health

#### Mental Health America of Virginia

https://mhav.org/

#### National Alliance for the Mentally Ill Virginia (NAMI Virginia)

https://namivirginia.org/

#### **Virginia Department of Behavioral Health and Developmental Services (DBHDS)**

http://www.dbhds.virginia.gov/

#### Virginia Office of Children's Services

http://www.csa.virginia.gov/

#### Voices for Virginia's Children

https://vakids.org/

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## Role of the Family in Treatment Programs

Over the past several years, the focus of mental health treatment and support for youth and families has increasingly been on evidence-based practices (National Alliance on Mental Illness [NAMI], 2007). Evidence-based practices are those that research has shown to be effective. However, although there is growing emphasis on evidence-based practices, it is equally important to emphasize the role of families as partners in the treatment process (NAMI).

To ensure successful treatment outcomes, it is crucial that family members are involved in child and adolescent services (Kutash & Rivera, 1995; Pfeifer & Strzelecki, 1990). Research has shown that the effectiveness of services hinges less on the particular type of treatment than on the family's participation in planning, implementing, and evaluating those services (Koren et al., 1997), as well as on their control over the child's treatment (Curtis & Singh, 1996; Thompson et al., 1997). Family participation promotes an increased focus on families, a provision of services in natural settings, a greater awareness of cultural sensitivity, and a community-based system of care. Research also confirms that family participation improves not only service delivery, but also treatment outcomes (Knitzer, Steinberg, & Fleisch, 1993).

There is a growing body of evidence indicating that children from vulnerable populations, children of single mothers, and children who live in poverty are more likely to exhibit the most serious problems. They are also the most likely to prematurely terminate treatment (Kadzin & Mazurick, 1994). Additional research is necessary to determine the factors that contribute to this early termination.

In recognition of this problem, it is important for mental health providers to ensure that families that have these characteristics are actively engaged in the services that their children receive in order to maximize the potential for successful outcomes. This goal is complicated by the fact that both families and providers may be confused and hesitant about the role that family members should play in treatment efforts. In addition, other barriers may preclude families from procuring high-quality mental health services for their children.

In an attempt to combat this problem, researchers have identified six broad roles that families should play in the treatment process (Friesen & Stephens, 1998). These roles are listed below:

Contributors to the Environment – Family members are a constant in the environment in which a child resides. Consequently, treatment providers often try to identify ways in which the behavior and interactions among family members influence the child's emotional and behavioral problems. With the assistance of the treatment provider, family members should consider ways to improve the home environment and the relationships within the family in order to provide the child with the most stable, supportive environment possible. In addition, family members should seek external support from their extended family and community to reduce the stress of raising a child with emotional or behavioral difficulties.

**Recipients of Service** – Family members are an important part of the therapeutic process. Service providers often focus on the family unit as a whole, creating interventions and strategies that target the health of the entire family. These interventions are intended to assess the strengths and weaknesses that exist within the family structure, to enhance the well-being of parents and other family members, and to help families locate support mechanisms in the community. The provider also assists family members in developing the skills necessary to support the special needs of the child. Services may include supportive counseling, parental training and education, development of coping skills and stress management techniques, respite care, parental support groups, transportation, and financial assistance.

**Partners in the Treatment Process** – Family members serve as equal contributors in the problem-solving process. They should work with treatment providers to identify the goals of treatment and to plan realistic strategies to achieve these goals. Additionally, family members should play a key role in implementing these strategies to help ensure that treatment goals are met. When performing these functions, family members should not be afraid to ask questions and to voice their opinions and preferences. It is crucial that they are fully informed and that their preferences are considered in all treatment decisions.

Service Providers – The treatment process is incomplete unless family members also provide services to the child. Family members are responsible for providing information and emotional support to the child and to other family members, and for filling in the gaps in the services being received by the child. Furthermore, they often coordinate services by requesting and convening meetings and transporting the child to appointments. It is a crucial role, the importance of which cannot be overstated. Parents and caregivers need to remain vigilant and involved in all aspects of the child's treatment. This includes keeping all follow-up appointments, becoming knowledgeable about any prescribed medications, and keeping track of all treatments that have been unsuccessful.

**Advocates** – Family members often serve as their child's only voice in the mental health system. They should therefore actively advocate for the child to ensure that he or she receives appropriate services. They also must voice any concerns regarding undesirable practices and policies. There are several local, state, and national organizations that can assist parents and caregivers in these efforts, allowing them to serve as part of a larger voice in their communities.

**Evaluators and Researchers** – It is important that families participate in research and evaluation activities so that their opinions can be heard regarding which treatments and services are most beneficial and convenient. The input of family members is crucial to ensure that all children receive services that are efficient and effective.

Because family members play important supporting roles in combating mental health disorders, it is important that they assume each of these roles in order to provide the effective support network that is necessary for the child's continued improvement. Family members who support and encourage their child and create a favorable environment for services will maximize the potential for successful outcomes.

The following information is attributed to the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA, 2000). Families must recognize that, although they are obtaining services for their child, they are the experts in understanding the following:

- How their child responds to different situations;
- Their child's strengths and needs;
- What their child likes and dislikes; and
- What has worked and has not worked in helping their child.

Families are ultimately responsible for determining what services and supports their children receive. Thus, family members must communicate to service providers their children's strengths and weaknesses, as well as their own priorities and expectations. They must also not hesitate to inform service providers if they believe treatment is not working so that appropriate modifications can be made (SAMHSA, 2000).

These recommendations also hold true for children who come into contact with the juvenile justice system. Family involvement is particularly critical for these youth to ensure positive outcomes (Osher & Hunt, 2002). It is imperative that family members provide information on the child's diagnosis and treatment history, use of medications, education history and status (including whether the child is enrolled in special education), and any other special circumstances that affect the child (Osher & Hunt). It is also important that they communicate their ability to participate in treatment. Ideally, families should be involved in decision-making and treatment at each stage of service provision (Osher & Hunt). Families and juvenile justice officials must cooperate to ensure that all have mutual responsibility for the child's outcomes (Osher & Hunt).

Without family involvement, it is extremely difficult for service providers to ensure that the gains achieved by the child in treatment are maintained and solidified. Moreover, the combined efforts of service providers, family members, and advocates are necessary to ensure that the services provided in the community effectively meet the needs of all children and families. It is important that parents and caregivers understand the results of any evaluation, the child's diagnosis, and the full range of treatment options. If parents are not comfortable with a particular clinician or treatment option or are confused about a specific recommendation, they should consider seeking a second opinion.

If medication is suggested as a treatment option, families must be informed of all associated risks and benefits. In addition, children and adolescents who are taking psychotropic medications must be closely monitored and frequently evaluated by qualified mental health providers (NAMI). The decision about whether to medicate a child as part of a comprehensive treatment plan should be made only after parents carefully weigh these factors (NAMI, 2007). Figure 1 outlines questions parents should ask about treatment services.

#### Figure 1

### Questions Parents or Caregivers Should Ask About Treatment Services

Before a child begins treatment, parents should ask the following:

- Does my child need additional assessment and/or testing (medical, psychological, etc.)?
- What are the recommended treatment options for my child?
- Why do you believe treatment in this program is indicated for my child? How does it compare to other programs or services that are available?
- What are the advantages and disadvantages of the recommended service or program?
- How long will treatment take?
- What will treatment cost, and how much of the cost is covered by insurance or public funding? Will we reach our insurance limit before treatment is completed?
- How will my child continue education while in treatment?
- Does my child need medication? If so, what is the name of the medication that will be prescribed? How will it help my child? How long before I see improvement? What are the side effects that occur with this medication?
- What are the credentials and experience of the members of the treatment team?
- How frequently will the treatment sessions occur?
- Will the treatment sessions occur with just my child or the entire family?
- How will I be involved with my child's treatment?
- How will we know if the treatment is working? What are some of the results I can expect to see?
- How long should it take before I see improvement?
- What should I do if the problems get worse?
- What are the arrangements if I need to reach you after-hours or in an emergency?
- As my child's problem improves, does this program provide less intensive/step-down treatment services?
- How will the decision be made to discharge my child from treatment?
- Once my child is discharged, how will it be decided what types of ongoing treatment will be necessary, how often, and for how long?

Source: American Academy of Child & Adolescent Psychiatry (AACAP), 2000.

#### **Supplementary Issues for Families**

Continuous news coverage of events such as natural disasters, catastrophic events, and violent crime may cause children to experience stress, anxiety, and fear (AACAP, 2002). In addition, some children may be unable to distinguish the difference between reality and the fantasy presented in the media (AACAP, 2001). As a result, children may be exposed to behaviors and attitudes that can be overwhelming or difficult to understand (AACAP, 2001). Caregivers should

be made aware that violent media images can have a greater impact upon children with emotional and behavioral issues than might otherwise be the case (AACAP, 2015).

#### **Systems of Care and Family Involvement**

Unless otherwise cited, information in this section is attributed to Systems of Care: A Framework for System Reform in Children's Mental Health (Stroul, 2002). A system of care is defined as "a comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of children and their families." It is not a program, but a philosophy. According to the primary values of the systems-of-care philosophy, services for children are:

- Community-based;
- Child-centered and family-focused; and
- Culturally competent.

Families are designated partners in the design of effective mental health services and supports. Families have a primary decision-making role in the care of their own children, as well as in the policies and procedures governing care for all children in their communities. This includes:

- Choosing supports, services, and providers
- Setting goals
- Designing and implementing programs
- Monitoring outcomes
- Partnering in funding decisions
- Determining the effectiveness of all efforts to promote the mental health and well-being of children and youth (AACAP, 2009)

Systems of care establish partnerships that work because the system is guided by the family. They use the family's expertise to steer decision-making in service and system design, operation, and evaluation. In recent years, studies have found that children whose families were involved in their treatment experienced improved educational outcomes and well-being. They also spent less time in out-of-home placements and residential settings (Jivanjee et al., 2002).

While families must take care to ensure that their child is properly treated, they must also understand that the family may also require support. Family members often experience considerable stress physically, emotionally, socially, and spiritually due to both the child's health problems and the stress of interacting with medical professionals. Ensuring that the family is also well supported can empower the family to support the child's treatment (SAMHSA, n.d.).

#### **Resources and Organizations**

#### **American Academy of Family Physicians**

https://www.aafp.org

#### American Association of Child & Adolescent Psychiatry (AACAP)

http://www.aacap.org/

#### **American Psychiatric Association (APA)**

http://www.psych.org

#### American Psychological Association (APA)

http://www.apa.org/

#### Familydoctor.org

https://familydoctor.org/

#### **Medscape Today Resource Centers (from WebMD)**

https://www.medscape.com/internalmedicine

#### **Mental Health America (MHA)**

http://www.mentalhealthamerica.net/

#### National Alliance for the Mentally Ill (NAMI)

https://www.nami.org/

#### **National Mental Health Information Center**

Child, Adolescent and Family Branch, Center for Mental Health Services https://www.samhsa.gov/children

#### National Technical Assistance Center for Children's Mental Health

https://gucchdtacenter.georgetown.edu/

#### **U.S. Department of Education**

Office of Special Education and Rehabilitative Services

https://www2.ed.gov/about/offices/list/osers/index.html?src=mr

#### U.S. Department of Health and Human Services

Centers for Disease Control and Prevention (CDC)

https://www.cdc.gov/

#### U.S. National Library of Medicine and the National Institutes of Health (NIH) Medline Plus

https://medlineplus.gov/

#### **Substance Abuse and Mental Health Services Administration (SAMHSA)**

National Registry of Evidence-based Programs and Practices

https://www.nrepp.samhsa.gov/landing.aspx

#### **Virginia Resources and Organizations**

#### Mental Health America of Virginia

https://mhav.org/

#### National Alliance for the Mentally Ill Virginia (NAMI Virginia)

https://namivirginia.org/

#### Virginia Department of Behavioral Health and Developmental Services (DBHDS)

http://www.dbhds.virginia.gov/

#### Virginia Office of Children's Services

http://www.csa.virginia.gov/

#### **Voices for Virginia's Children**

https://vakids.org/

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# EY COMPONENTS OF SUCCESSFUL TREATMENT PROGRAMS

Integrated Programming – The "Systems" Approach
Screening and Assessment
Individualized Care Planning
Discharge Planning
Engaging Families in Treatment
Culturally-Competent Service Delivery
Psychosocial and Pharmacological Treatments

While studies have identified numerous strategies and techniques that are effective in the treatment of mental health issues, a growing body of research shows that there are several guiding principles that provide a foundation for any treatment program. These principles will be discussed in detail in the following paragraphs.

#### Integrated Programming – The "Systems" Approach

Research continues to support the idea that the mental health needs of children and adolescents are best served within the context of a "system of care" in which multiple service providers work together in an organized, collaborative way. The system-of-care approach encourages agencies to provide services that are child-centered and family-focused, community-based, and culturally competent. The guiding principles also call for services to be integrated. Linking child-serving agencies and programs allows for collaborative planning, development, and implementation of services. Additional information on systems of care is provided in the "Role of the Family" section.

Systems of care produce important system improvements. For example, studies have shown that systems of care improve the functional behavior of children and reduce the use of residential and out-of-state placements. Parents also appear to be more satisfied with services provided within systems of care than with more traditional service delivery systems.

The Virginia Department of Behavioral Health and Developmental Services (VDBHDS) emphasizes the need for agency collaboration at both the state and local levels (2004). This can be achieved by promoting integration of services and establishing policies that require service providers to conduct a single, comprehensive intake addressing the areas of mental health, intellectual disability, and substance abuse. Moreover, community partnerships can be strengthened or enhanced to improve the delivery of child and adolescent mental health services.

#### **Screening and Assessment**

Comprehensive assessment, screening, and evaluation are necessary for children and adolescents experiencing a mental health crisis. Children should also be screened to identify potential

delayed or atypical development, thus determining the appropriate level of assessment (Pires, 2002). In addition to screening, assessment and evaluation collectively address the needs and services of the child and family (Pires).

Parents of youth who are identified with a possible problem should be offered a full assessment by a professional clinician. A qualified mental health professional can determine whether a comprehensive psychiatric evaluation for serious emotional behavior problems is necessary (American Academy of Child & Adolescent Psychiatry [AACAP], 2005). Such a step will lead to accurate assessment and, if needed, appropriate, individualized treatment. In addition, every step of the assessment process must include parental consent and youth assent (Substance Abuse and Mental Health Services Administration [SAMHSA], 2011).

#### **Individualized Care Planning**

In order to make certain that there is a continuity of treatment, a framework should be established that ensures that a child can transition with ease from one service to another. The efficiency of these transitions is enhanced through the creation of effective individualized service plans. These plans, which are targeted to the child's specific needs, identify problems, establish goals, and specify appropriate interventions and services. Developed in partnership with the child and family, an individualized service plan allows for services to be matched with the unique potential and needs of each child and family (Stroul & Friedman, 2011).

Once screening and assessment have taken place, an individual care plan ensures that the distinct needs of the child are met. The goal is to plan and provide appropriate services and supports to the child. Elements that must be acknowledged include building trust, engaging the family, and tailoring family supports (Pires, 2002). Some components to be included in such a plan are:

- Background information and family assessment
- Identifying information
- Child development and behavior
- Needs
- Family functioning style
- Social support network
- Safety issues and risks
- Goals
- Sources of support and/or resources
- Action plan
- Progress evaluation

#### **Discharge Planning**

Service providers have found that a breakdown in the system of care is frequently encountered in the area of discharge planning. A discharge plan should be created whenever a child is transitioning from inpatient or residential treatment back into the community. These plans should be updated in consultation with the child's family before the child is released from treatment. They should describe the therapy and services that were provided in the facility and recommend any necessary follow-up services, which should then be coordinated by a case manager.

Although they are frequently overlooked, discharge plans are a key component of a comprehensive system of care, as they help to ensure that the gains made in an inpatient or residential setting are continued once the child returns to the community.

#### **Engaging Families in Treatment**

Service providers and researchers have increasingly realized the important role that families play in the treatment of children with mental health disorders. The mental health system has taken steps to make families partners in the delivery of mental health services for children and adolescents (U.S. Department of Health and Human Services, 1999). For further discussion of the roles that families should play in treatment services, see the "Role of the Family in Treatment Programs" section of the *Collection*.

Engagement involves the participation of people who both deliver and seek services. With effective engagement, the likelihood of ongoing participation in services and supports increases (National Alliance on Mental Illness [NAMI], 2016). When care is respectful, compassionate, and centered on an individual's life goals, the likelihood of recovery is sharply increased.

According to the New Freedom Commission on Mental Health established by President George W. Bush, local, state, and federal officials must engage families in planning and evaluating treatment and support services (2003). The direct participation of families in developing a range of community-based, recovery-oriented treatment and support services is important. Families of children with serious emotional disturbances have a key role in mental health care delivery in that they can advocate for a system that focuses on recovery through the use of appropriate evidence-based treatments.

The New Freedom Commission also specifies that mental health care should be consumer and family driven. Consumers their families should be encouraged to be fully involved in care, which will help promote a recovery-based mental health system. Families can take part in this process by becoming educated about the appropriate treatments for their child, as well as the provider qualifications necessary to delivery these treatments. For more information about mental health providers' qualifications, please see the "General Description of Providers" section of the *Collection*.

#### **Culturally-Competent Service Delivery**

Virginia, like the nation as a whole, is becoming more racially diverse. The minority share of the population has increased from 29.8 percent in 2000 to 35.2 percent in 2010 (Sturtevant, 2011). During this period, the biggest gain was among Virginia's Hispanic population, which grew by more than 300,000, or 92 percent (Cai, 2011). The Asian population grew by 68.3 percent, and the population of all other minority races (including persons of two or more races) grew by 50.8 percent (Sturtevant). This increase in diversity has significant implications for service providers in the Commonwealth, as cultural factors are becoming increasingly important in the evaluation and treatment of mental health disorders.

Culture has been found to influence many aspects of mental health disorders. Individuals from specific cultures may express and manifest their symptoms in different ways. They may also differ in their styles of coping, their use of family and community supports, and their willingness

to seek and continue treatment. Moreover, clinicians may be influenced by their own cultural values, which may affect diagnosis, treatment, and service delivery decisions (U.S. Department of Health and Human Services, 2001).

The variability within a culture and among different cultural groups is described in Table 1.

The following is attributed to Kumpfer and Alvarado (1998). Cultural competency involves addressing the various folkways, mores, traditions, customs, rituals, and dialects that are specific to each culture and ethnicity (Saldana, 2001). Research has shown that tailoring interventions to the cultural traditions of the family improve outcomes. Culturally-relevant values can be integrated into existing model programs for a variety of ethnic groups. Such an approach can address the various nuances that cultures may exhibit, such as specific values and beliefs. These cultural beliefs should be incorporated into an organized, culturally sensitive treatment framework.

Table 1

Addressing Cultural Variability

Variability Factor	Description
Acculturation	This reflects the extent to which a person is familiar with and proficient within U.S. mainstream culture.
Poverty	There may be difference in resources, as well as a lack of awareness of traditional mental health interventions and the importance of compliance.
Language	Clients may not be as fluent in English as they are in their native language. Different dialects within the same language may also create communication barriers.
Transportation, housing and childcare	A lack of available resources and supports may interfere with access to treatment and adherence with provider expectations.
Reading ability/ educational background	Individuals may vary substantially in academic experience. This is true within ethnic subgroups, as well as between subgroups.
Beliefs	People from diverse cultures vary in their beliefs about what is considered "illness," what causes an illness, what should be done to address an illness, and what the treatment outcome should be. Providers cannot assume their clients' views match theirs.
Physical characteristics	People of different ethnic backgrounds sometimes differ in their appearance, even within the same ethnic group.

Source: Saldana, 2001.

Cultural differences may also affect the success of mental health services. The mental health treatment setting relies significantly on language, communication, and trust between patients and providers. In addition, children may be reticent to share elements of their cultural orientation with persons who do not share their culture. Therefore, therapeutic success may hinge on the clinician's ability to understand a patient's identity, social supports, self-esteem, and perception

of stigma. Consequently, mental health service providers must recognize underlying cultural influences so they can effectively address the mental health needs of each segment of the community (U.S. Department of Health and Human Services, 1999).

Culturally competent treatment programs are founded upon an awareness of and respect for the values, beliefs, traditions, customs, and parenting styles of all individuals who reside in the community. Providers should be aware of the impact of their own culture on the therapeutic relationship with their clients and consider these factors when planning and delivering the services for youth and their families. Ideally, culturally competent programs include multilingual, multicultural staff and provide extensive community outreach (Cross et al., 1989).

The services offered within a community should also reflect a respect for cultural diversity. For example, the inclusion of extended family members in treatment efforts should be incorporated within certain treatment approaches, when appropriate. It would also be beneficial for mental health agencies to display culturally relevant pictures and literature in order to show respect and increase consumer comfort with services. Finally, agencies should consider the holidays or work schedules of consumers when scheduling office hours and meetings (Cross et al., 1989).

Cultural differences other than ethnicity must also be considered. For example, Americans living in isolated and impoverished rural areas may display unique characteristics that present barriers to mental health services. Some may not seek care because of a perceived stigma attached to mental health disorders, a lack of understanding about mental illnesses and treatments, a lack of information about where to go for treatment, or an inability to pay for care. Furthermore, factors such as poverty and geographic isolation may affect the quality of mental health care available to these individuals. These issues are further complicated by the limited availability of mental health specialists, such as psychiatrists, psychologists, psychiatric nurses, and social workers, in rural areas (National Institute of Mental Health [NIMH], 2000).

It is important to consider the impact of culture on mental health service delivery. Culturally competent programming has been found to promote service utilization for all ages, including children (Snowden & Hu, 1997). Furthermore, children and families enrolled in mental health programs that are aligned with a community's culture are less likely to drop out of treatment than those in mainstream programs (SAMHSA, 2014; Takeuchi, Sue, & Yeh, 1995). Culturally competent training and service planning serve as important components of the mental health delivery system.

#### **Psychosocial and Pharmacological Treatments**

Because of the increasing recognition of the impact mental health disorders have upon children and adolescents, there has been greater scrutiny regarding the effectiveness and safety of mental health interventions used to treat children. Accordingly, the number of scientific studies of treatment effectiveness has risen dramatically. Several federally sponsored clinical trials have been conducted to address the effectiveness of interventions for childhood disorders (American Psychological Association [APA], 2006).

Child and adolescent mental health treatments may be psychosocial, pharmacological, and/or combined. Psychosocial treatments are treatments that include different types of psychotherapy

and social and vocational training. These interventions aim to provide support, education, and guidance to children with mental health conditions (NAMI, 2015). Pharmacological treatments use medication to treat the mental health disorder.

The APA's working group on psychotropic medications recommends that, for most children and adolescents, psychosocial interventions should be considered first (APA, 2006). The working group noted a variety of reasons why psychosocial interventions were preferred, with the primary reason being that these interventions are safer than psychotropic medications (APA). There are vast developmental differences in child and adolescent populations that influence physiological, cognitive, behavioral, and affective functioning. Development also has implications with respect to medication management. For instance, physiological differences can result in markedly different rates of medication absorption, distribution in the body, and metabolism among youth of different ages and stages of development (Brown & Sammons, 2002, as cited by APA). Children are also less able than adults to accurately describe changes in their physiological and psychological functioning, the course of these changes over time, and any adverse effects of psychotropic medications. In addition, parents are responsible for both the decision to use pharmacotherapy and the administration of medication. In the school setting, it may be the school nurse or the teacher who administers medication. As a result, parents' and school personnel's attitudes toward medication may influence whether a child adheres to medical regimens. For these reasons, the unique issues in child and adolescent psychopharmacology must be considered when prescribing and monitoring medication in pediatric populations (APA).

If medication is recommended as a treatment, the physician recommending its use should be experienced in treating psychiatric illnesses in children and adolescents (AACAP, 2012). He or she should fully explain the reasons for medication use, the benefits the medication should provide, the possible risks and adverse effects, and any other treatment alternatives. When pharmacological treatments are necessary, their use should be carefully monitored, and dosage should be tapered off as soon as possible (Tweed et al., 2012). In addition, psychiatric medication should not be used alone. The use of medication should be based on a comprehensive psychiatric evaluation and be one part of a comprehensive treatment plan.

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# Reference Chart of Evidence-Based Practices

## Findings by Treatment Type for Children and Adolescents

Please refer to individual sections of the Collection for discussion of a particular disorder.

#### **ADJUSTMENT DISORDER**

What Works	
There are no evidence-based practices a	at this time
What Seems to Work	
Interpersonal psychotherapy (IPT)	IPT helps children address problems to relieve depressive symptoms.
Cognitive behavioral therapy (CBT)	CBT is used to improve age-appropriate problem-solving skills, communication skills, and stress management skills. It also helps the child's emotional state and support systems to enhance adaptation and coping.
Stress management	Stress management is particularly beneficial in cases of high stress and helps the youth learn how to manage stress in a healthy way.
Group therapy	Group therapy among of likeminded/afflicted individuals can help group members cope with various features of adjustment disorders.
Family therapy	Family therapy is helpful for identifying needed changes within the family system. These changes may include improving communication skills and family interactions and increasing support among family members.
What Does Not Work	
Pharmacology alone	Medication is seldom used as a singular treatment because it does not provide assistance to the child in learning how to cope with the stressor.

## **A**NOREXIA **N**ERVOSA

What Works	
Nutritional rehabilitation	Entails developing meal plans and monitoring intake of adequate nutrition to promote healthy weight gain.
Family psychotherapy	Family members are included in the process to assist in reduction of symptoms and modify maladaptive interpersonal patterns.
In-patient behavioral programs	Individuals are rewarded for engaging in healthy eating and weight-related behaviors.
What Seems to Work	
Cognitive behavioral therapy (CBT)	Needs further study to be well established; it is used to change underlying eating disorder cognitions and behaviors.
Pharmacological treatments	Used primarily after weight restoration to minimize symptoms associated with psychiatric comorbidities.

# ANOREXIA NERVOSA (CONT.)

Not Adequately Tested	
Individual psychotherapy	Controlled trials have not supported this treatment; however, it may be beneficial during the refeeding process and to minimize comorbid symptoms.
What Does Not Work	
Group psychotherapy	May stimulate the transmission of unhealthy techniques among group members, particularly during acute phase of disorder.
12-step programs	Not yet tested for their efficacy; discouraged as a sole treatment.
Tricyclic antidepressants	Tricyclic antidepressants are contraindicated and should be avoided in underweight individuals and in individuals who are at risk for suicide.
Somatic treatments	To date, treatments such as vitamin and hormone treatments and electroconvulsive therapy show no therapeutic value.

## **ANXIETY DISORDERS**

What Works	
Behavioral & cognitive behavioral therapy (CBT)	Treatment that involves exposing youth to the (non-dangerous) feared stimuli and challenging the cognitions associated with the feared stimuli with the goal of the youth's learning that anxiety decreases over time.
Selective serotonin reuptake inhibitors (SSRI)	Treatment with certain SSRIs have been proven to help with anxiety; however, SSRIs may increase suicidal ideation in some youth.
Benzodiazepines	While proven effective, not a first choice treatment because of an increase in the risk of behavioral disinhibition.
What Seems to Work	
Educational support	Psychoeducational information on anxiety provided to parents, usually in a group setting.
Computer-based behavioral & cognitive behavioral therapy (CBT)	CBT administered electronically to eliminate long waiting periods or lack of clinical experts in a given area.
Not Adequately Tested	
Play therapy	Therapy using self-guided play to encourage expression of feelings.
Antihistamines or herbs	No controlled studies on efficacy.
Psychodynamic therapy	Therapy designed to uncover unconscious psychological processes to alleviate the tension thought to cause distress.
Biofeedback	Minimal support for efficacy.
Antipsychotics/neuroleptics	High level of risk of impaired cognitive functioning and tardive dyskinesia with long-term use; contraindicated in youth who do not also have Tourette's syndrome or psychosis.

# ATTENTION-DEFICIT/HYPERACTIVITY DISORDER (ADHD)

What Works	
Behavioral classroom management (BCM)	BCM uses contingency management strategies, including teacher-implemented reward programs, token systems, time-out procedures, and daily report cards (DRCs). Clinicians or parents may work in consultation with teachers to develop a classroom treatment plan.
Behavioral parent training (BPT)	BPT teaches the parent to implement contingency management strategies similar to BCM techniques at home.
Intensive behavioral peer intervention (BPI)	Intensive BPI is conducted in recreational settings, such as summer treatment programs (STPs). STPs have demonstrated effectiveness and are considered well-established. However, STPs are less feasible to implement than other evidence-based practices.
Stimulant: d-Amphetamine	Short-acting: Adderall, Dexedrine, DextroStat Long-acting: Dexedrine Spansule, Adderall XR, Lisdexamfetamine
Stimulant: Methylphenidate	Short-acting: Focaline, Methylin, Ritalin Intermediate-acting: Metadate ER, Methylin ER, Ritalin SR, Metadate CD, Ritalin LA Long-acting: Concerta, Daytrana patch, Focalin XR
Serotonin and norepinephrine reuptake inhibitor (SNRI): atomoxetine	Atomoxetine is unique in its ability to act on the brain's norepinephrine transporters without carrying the same risk for addiction as other medications.
What Does Not Work	
Cognitive, psychodynamic, and client-centered therapies	Traditional talk therapies and play therapy have been demonstrated to have little to no effect on ADHD symptoms. ADHD is best treated with intensive behavioral interventions in the youth's natural environments.
Office-based social skills training	Once-weekly office-based training, either one-on-one or in a group setting, have not led to significant improvement in social skills. (However, intensive group social skills training that uses behavioral interventions, such as STPs, are considered well-established.)
Dietary interventions	Interventions include elimination of food additives, elimination of allergens/sensitivities, and use of nutritional supplements.
Antidepressants	These include bupropion (Wellbutrin), imipramine (Tofranil), nortriptyline (Pamelor, Aventil), clonidine (Catapres) and guanfacine (Tenex).

# AUTISM SPECTRUM DISORDER (ASD)

What Works	
Behavioral interventions	Includes antecedent interventions and consequent interventions.
Discrete trial teaching or training (DTT)	A type of behavioral intervention that uses operant learning techniques to change behavior. Also known as the ABC model (action request, behavior, consequence).
Cognitive behavioral intervention package	CBT modified for ASD youth.
Comprehensive behavioral treatment for young children (CBTYC)	Also known as applied behavior analysis (ABA), early intensive behavioral intervention (EIBI), and behavioral inclusive programs.
Language training (production)	Targets the ability to communicate verbally.

# AUTISM SPECTRUM DISORDER (ASD) (CONT.)

Modeling	Involves demonstrating a target behavior to encourage imitation.
Naturalistic teaching strategies (NTS)	Child-directed strategies that use naturally occurring activities to increase adaptive skills.
Parent training package	Involves training parents to act as therapists.
Peer training package	Trains peers on how to behavior during social interactions with a youth with ASD.
Learning experience: An alternative program (LEAP)	A type of peer training program for peers, teachers, parents, and others.
Pivotal response training (PRI)	Involves targeting pivotal behaviors related to motivation to engage in social communication, self-initiation, self-management, and responsiveness to multiple cues.
Schedules	Used to increase independence in youth with ASD.
Scripting	Providing scripted language to be used as a model in specific situations.
Self-management	Strategies that involve teaching youth to track performance while completing an activity.
Social skills package	Aims to provide youth with the skills (such as making eye contact appropriately) necessary to participate in social environments.
Story-based intervention	Use stories to increase perspective taking skills.
What Seems to Work	
Augmentative and alternative communication devices	Communication systems designed to complement speech (pictures, symbols, etc.).
Developmental relationship-based treatment	Programs that emphasize the importance of building social relationships by using the principals of developmental theory.
Exercise	Uses physical exertion to regulate behavior.
Exposure package	Requires youth to face anxiety-provoking situations.
Functional communication training (fct)	Behavioral method that replaces disruptive or inappropriate behavior with more appropriate and effective communication.
Imitation-based intervention	Relies on adults imitating the actions of a child.
Initiation training	Involves directly teaching individuals with ASD to initiate interactions with their peers.
Language training (production and understanding)	Aims to increase both speech production and understanding of communicative acts.
Massage therapy	Involves the provision of deep tissue stimulation.
Multi-component package	Involves a combination of multiple treatment procedures that are derived from different fields of interest or different theoretical orientations.
Music therapy	Aims to teach individual skills or goals through music.
Picture exchange communication system	Involves the application of a specific augmentative and alternative communication system for youth with limited communication skills.
Reductive package	Relies on strategies designed to reduce problem behaviors without increasing alternative appropriate behaviors.
Sign instruction	Teaches sign language as a means of communicating.

## **AUTISM SPECTRUM DISORDER (ASD) (CONT.)**

Social communication intervention	Targets some combination of social communication impairments.
Structured teaching	Relies heavily on the physical organization of setting, predictable schedules, and individualized use of teaching methods.
Technology-based intervention	Presents instructional materials using the medium of computers or related technologies.
Theory of mind training	Aims to teach youth to recognize and identify the mental states of others.
Not Adequately Tested	

- Animal-assisted therapy (e.g., hippotherapy: the use of horseback riding as a therapeutic or rehabilitative treatment)
- Auditory integration training
- Concept mapping
- DIR/Floor time
- Gluten-free and/or casein-free diet
- Facilitated communication
- Movement-based intervention
- Sensory integration
- Shock therapy
- Social-behavioral learning strategy (e.g., SODA)
- Social cognition/social thinking Intervention program
- Holding therapy

#### **BINGE EATING DISORDER**

What Works	
There are no evidence-based practices at this time.	
What Seems to Work	
Cognitive behavioral therapy (CBT)	The most effective independent treatment option; it is used to change underlying eating disorder cognitions and behaviors.
Interpersonal psychotherapy (IPT)	Attempts to reduce the use of binge eating as a coping mechanism by supporting the development of healthy interpersonal skills.
Pharmacological treatments	Antidepressants, namely SSRIs, have effectively reduced binge/purging behaviors, as well as comorbid psychiatric symptoms.
Not Adequately Tested	
Dialectical behavior therapy (DBT) Mindfulness and yoga-based interventions	These treatments are suggested as future areas of research.
What Does Not Work	
Pharmacological treatments	Although may reduce binge eating in high doses, does not necessarily help with weight loss; in addition, very high placebo response rate and relapse rate.
Nutritional rehabilitation and counseling	Although initial weight loss is associated with these treatments, weight is commonly regained.
12-step programs	Discouraged as a sole treatment; does not address nutritional or behavioral concerns.

## **BIPOLAR AND RELATED DISORDERS**

What Works	
There are no evidence-based practices at this time.	
What Seems to Work	
Psychopharmacological treatment	Mood stablizers/Anticonvulsants; second-generation antipsychotics.
Family-focused psychoeducational therapy (FFT)	Helps youth make sense of their illness and accept it and also to better understand use of medication. Also helps to manage stress, reduce negative life events, and promote a positive family environment.
Child- and family-focused cognitive behavioral therapy (CFF-CBT)	Emphasizes individual psychotherapy with youth and parents, parent training and support, and family therapy.
Multifamily psychoeducation groups (MFPG)	Youth and parent group therapy have been shown to increase parental knowledge, promote greater access to services, and increase parental social support for youth.
Not Adequately Tested	
Interpersonal social rhythm therapy (IPSRT)	Works to minimize the effects of life stressors by helping youth establish regular patterns of sleep, exercise, and social interactions.
Omega-3 fatty acids	Unclear if supplementation helps with depressive symptoms when used in conjunction with other treatments.
Topiramate; Oxcarbazepine	Anticonvulsants; not proven to be effective in youth or adults.
Dialectical behavior therapy (DBT)	Family skills training and individual therapy; not proven to help with mania or interpersonal functioning.

## **BULIMIA NERVOSA**

What Works	
Cognitive behavioral therapy (CBT)	The most effective independent treatment option; it is used to change underlying eating disorder cognitions and behaviors.
Combined treatments	A combination of CBT and pharmacotherapy seems to maximize outcomes.
What Seems to Work	
Pharmacological treatments	Antidepressants, namely SSRIs, have effectively reduced binge/purging behaviors, as well as comorbid psychiatric symptoms.
Not Adequately Tested	
Individual psychotherapy	Compared to CBT, few individual therapeutic approaches have been effective in reducing symptoms.
Family therapy	May be more beneficial than individual psychotherapy, but outcomes should be considered preliminary at this time.
What Does Not Work	
Bupropion	Bupropion has been associated with seizures in purging individuals with BN and is contraindicated.
Monoamine oxidase inhibitors (MAOIs)	MAOIs are potentially dangerous in individuals with chaotic binging and purging and their use is contraindicated.
12-step programs	Discouraged as a sole treatment; do not address nutritional or behavioral concerns.

## DEPRESSIVE DISORDERS - CHILDREN

What Works	
Stark's cognitive behavioral therapy (CBT) - child-only group or child group plus parent component	Stark's CBT includes mood monitoring, mood education, increasing positive activities and positive self-statements, and problem solving.
Fluoxetine (SSRI) in combination with CBT	Fluoxetine is the only antidepressant approved by the FDA for use in children. For moderate to severe depression, pharmacological treatment in combination with psychosocial therapy may be warranted. However, because SSRIs can increase suicidal behavior in youth, children taking fluoxetine must be closely monitored.
What Seems to Work	
Penn prevention program (PPP)	PPP is a CBT-based program that targets pre-adolescents and early adolescents who are at-risk for depression.
Self-control therapy	Self-control therapy is a school-based CBT that focuses on self-monitoring, self-evaluating, and causal attributions.
Behavioral therapy	Includes pleasant activity monitoring, social skills training, and relaxation.

## DEPRESSIVE DISORDERS - ADOLESCENTS

What Works	
Cognitive behavioral therapy (CBT) provided in a group setting	CBT for depression focuses on identifying thought and behavioral patterns that lead to or maintain the problematic symptoms.
Interpersonal therapy (IPT) provided individually	In IPT, the therapist and patient address the patient's interpersonal communication skills, interpersonal conflicts, and family relationship problems.
Fluoxetine (SSRI) in combination with CBT	Fluoxetine is the only antidepressant approved by the FDA for use in children. For moderate to severe depression, pharmacological treatment in combination with psychosocial therapy may be warranted. However, because SSRIs can increase suicidal behavior in youth, children taking fluoxetine must be closely monitored.
What Seems to Work	
CBT in a group or individual setting with a parent/family component	CBT for depression focuses on identifying thought and behavioral patterns that lead to or maintain the problematic symptoms.
Adolecent coping with depression (CWD-A)	CWD-A includes practicing relaxation and addressing maladaptive patterns in thinking, as well as scheduling pleasant activities, and learning communication and conflict resolution skills.
Interpersonal psychotherapy for depressed adolescents (IPT-A)	IPT-A addresses the adolescent's specific interpersonal relationships and conflicts, and helps the adolescent be more effective in their relationships with others.
Physical exercise	Physical exercise has shown promise in improving symptoms of depression in adolescents. Group-based and supervised light- or moderate-intensity exercise activities 3 times a week for a period of between 6 to 11 or 12 weeks may bring about an improvement in depression. Additional research is need.
Not Adequately Tested	
Dietary supplements	Supplements such as St. John's Wort, SAM-e, and Omega-3 have not been adequately tested and may have harmful side effects or interact with other medications. Parents should discuss supplement use with a mental health care professional.
What Does Not Work	
Tricyclic antidepressants	These antidepressants can have problematic side effects and are not recommended for children or adolescents with depression.

# DISRUPTIVE, IMPULSE-CONTROL, AND CONDUCT DISORDERS

What Works	
Assertiveness training	School-based group treatment for middle- school youth.
Parent management training (PMT)  • Helping the Noncompliant Child  • Incredible Years  • Parent-child interaction therapy  • Parent MT to Oregon model  • Positive parenting program	PMT programs focus on teaching and practicing parenting skills with parents or caregivers.
Multisystemic therapy (MST)	MST is an integrative, family-based treatment for youth with serious antisocial and delinquent behavior. Interventions last 3-5 months and focus on improving psychosocial functioning.
Cognitive behavioral therapy (CBT)	CBTs emphasize problem-solving skills and anger control/coping strategies.
CBT & parent management training	Combines CBT and PMT.
What Seems to Work	
Multidimensional treatment foster care	Community-based program alternative to institutional, residential, and group care placements for use with severe chronic delinquent behavior. Foster parents receive training and provide intensive supported treatment within the foster home.
Not Adequately Tested	
Atypical antipsychotics medications	Risperidone (Risperdal), quetiapine (Seroquel), olanzapine (Zyprexa), and aripiprazole (Abilify); limited evidence for effectiveness in youth with ID or ASD.
Stimulant or atomoxetine	Methylphenidate, d-Amphetamine, atomoxetine; limited evidence when comorbid with primary diagnosis of ADHD.
Mood stabilizers	Divalproex sodium, lithium carbonate; limited evidence when comorbid with primary diagnosis of bipolar disorder.
Selective serotonin reuptake inhibitors (SSRIs)	Limited evidence when comorbid with primary diagnosis of depressive disorder.
What Does Not Work	
Boot camps, shock incarcerations	Ineffective at best; can lead worsening of symptoms.
Dramatic, short-term, or talk therapy	Little to no effect as currently studied.

## **INTELLECTUAL DISABILITY**

What Works	
Behavioral interventions, such as positive behavior support (PBS)	Behavioral interventions analyze the cause of a negative behavior and how it is being reinforced, and then offer techniques targeted to promoting positive behaviors.
What Seems to Work	
Psychotropic medication for co- occurring mental health disorders	Prescribed to treat comorbid disorders. Because these medications have not been studied in ID populations, they should only be used when other therapies do not address symptoms and in conjunction with appropriate behavioral interventions.
Not Adequately Tested	
Psychotropic medications to treat challenging behaviors	Psychotropic medications are sometimes used "off label" to treat challenging behaviors such as aggression. These medications should be used with caution and only when necessary. They should never be used for the convenience of caregivers.

# FIRESETTING, JUVENILE

What Works		
There are no evidence-based pr	There are no evidence-based practices at this time	
What Seems to Work		
Cognitive behavioral therapy	Structured treatments designed to intervene with children who set fires.	
Fire safety education	Education includes information about the nature of fire, how rapidly it spreads, and its potential for destructiveness, as well as information about how to maintain a fire-safe environment, utilizing escape plans and practice, and the appropriate use of fire.	
Firefighter home visit	Firefighters visit homes and explain the dangers of playing with fire to at-risk juveniles.	
What Does Not Work		
Ignoring the problem	Leaving youth untreated is not beneficial because they typically do not outgrow this behavior and ignoring these behaviors may increase dysfunctional behavior patterns.	
Satiation	Satiation, the practice of repetitively lighting and extinguishing fire, may cause the youth to feel more competent around fire and may actually increase the behavior.	
Burning the juvenile	Burning a juvenile to show the destructive force of fire is illegal/abusive. It will not decrease the likelihood of the juvenile setting fires or actually treat the problem.	
Scaring the juvenile	Scare tactics may produce the emotions or stimulate the actions the clinician is trying to prevent, particularly when family or social issues may trigger firesetting. Scare tactics may also trigger defiance, avoidance, or increase the likelihood that firesetting traits continue.	

## **MOTOR DISORDERS**

What Works	
Habit reversal therapy (HRT) for tic disorder	Treatment increases awareness to the feelings and context associated with the urge to tic and implements a competing and inconspicuous habit in place of the tic.
Comprehensive behavioral intervention for tics (C-BIT)	Combines habit reversal and other approaches like education, awareness via self-monitoring, relaxation techniques, and sometimes situational changes.
What Seems to Work	
Exposure with response prevention (ERP)	Consists of repeated, prolonged exposures to stimuli that elicit discomfort and instructions to refrain from any behavior that serves to reduce discomfort.
Pharmacotherapy	Medications may be considered for moderate to severe tics causing severe impairment in quality of life or when medication responsive psychiatric comorbidities are present that target both tic symptoms and comorbid condition.
Massed negative practice	Treatment involves children's over-rehearsal of target tic in high-risk situations.
What Does Not Work	
Deep brain stimulation	Surgical intervention; not recommended.
Repetitive transcranial magnetic stimulation (rTMS)	Safety in youth has not been established; not recommended.
Plasma exchange; Intravenous immunoglobulin (IVIG) treatment	Blood transfusions alter levels of plasma or immunoglobulin. While several of these treatments have been shown to be promising, they are not empirically supported and not recommended.
Dietary supplements (magnesium and vitamin B6); special diets	Supplements may have the potential to negatively interact with other pharmacological agents. Not recommended until safety in children is established.

## **NONSUICIDAL SELF-INJURY**

What Works	
There are no evidence-based practices at this time.	
What Seems to Work	
Cognitive behavioral therapy (CBT)	CBT involves providing skills designed to assist youth with affect regulation and problem solving.
Dialectical behavior therapy (DBT)	DBT emphasizes acceptance strategies and the development of coping skills.
Not Adequately Tested	
Problem solving therapy	Designed to improve an individual's ability to cope with stressful life experiences.
Pharmacological treatment	Evidence of the effectiveness of the use of medications, such as high-dose SSRIs, atypical neuroleptics, and opiate antagonists, is limited. In addition, some medications have been shown to increase suicidal ideation in children and adolescents.
Hospitalization	Because effectiveness is not consistently demonstrated, should be reserved for youth who express intent to die.

## **OBSESSIVE-COMPULSIVE AND RELATED DISORDERS**

What Works	
Cognitive behavioral therapy (CBT) with exposure and response prevention (ERP)	Treatment path with a consistent and compelling relationship between the disorder, the treatment, and the specified outcome. Combines training with exposure and preventing the accompanying response.
Family-focused individual CBT	Individual CBT that includes a focus on family involvement. It should be noted that the distinction of family focused here is meant to imply a format for treatment delivery.
SRIs	Clomipramine: Approved for children aged ten and older. Recommend periodic electrocardiographic (ECG) monitoring.
SSRIs	Fluoxetine (Prozac): Approved for children aged eight and older. Sertraline (Zoloft): Approved for children aged six and older. Fluoxamine (Luvox): Approved for children aged eight and older.
What Seems to Work	
Family focused group CBT	Studies show promising results but there have only been a small number of studies. However, each study addresses complex comorbidity and issues impacting community-based clinic treatment.
Not Adequately Tested	
CBT without ERP Psychodynamic therapy Client-centered therapy	Systematic controlled studies have not been conducted using these approaches.
Technology-based CBT	Results show preliminary support for telephone CBT and web-camera CBT. Although these results are encouraging, caution must be taken due to the small sample sizes and lack of active control groups.
What Does Not Work	
Antibiotic treatments	Antibiotic treatments are only indicated when the presence of an autoimmune or strep- infection has been confirmed and coincided with onset or increased severity of obsessive- compulsive disorder symptoms.
Herbal therapies	Herbs, such as St. John's Wort, have not been rigorously tested and are not FDA approved. In some instances, herbal remedies may make symptoms worse or interfere with pharmacological treatment.

# OFFENDING, JUVENILE

What Works	
Multisystemic therapy (MST)	An integrative, family-based treatment with a focus on improving psychosocial functioning for youth and families.
Functional family therapy (FFT)	A family-based program that focuses on delinquency, treating maladaptive and "acting out" behaviors, and identifying obtainable changes.
Treatment Foster Care Oregon (TFCO)	As an alternative to corrections or residential treatment, TFCO places juvenile offenders with carefully trained foster families who provide youth with close supervision, fair and consistent limits, consequences, and a supportive relationship with an adult. The program includes family therapy for biological parents, skills training and supportive therapy for youth, and school-based behavioral interventions and academic support.
What Seems to Work	
Family centered treatment (FCT)	FCT seeks to address the causes of parental system breakdown while integrating behavioral change. FCT provides intensive in-home services and is structured into four phases: joining and assessment, restructuring, value change, and generalization.
Brief strategic family therapy	A short-term, family-focused therapy that focuses on changing family interactions and contextual factors that lead to behavior problems.
Aggression replacement therapy (ART)	A short-term, educational program that focuses on anger management and provides youth with the skills to demonstrate non-aggressive behaviors, decrease antisocial behaviors, and utilize prosocial behaviors.
Cognitive behavioral therapy (CBT)	A structured, therapeutic approach that involves teaching youth about the thought-behavior link and working with them to modify their thinking patterns in a way that will lead to more adaptive behavior in challenging situations.
Dialectical behavior therapy	A therapeutic approach that includes individual and group therapy components and specifically aims to increase self-esteem and decrease self-injurious behaviors and behaviors that interfere with therapy.

## POST-TRAUMATIC STRESS DISORDER

What Works	
Trauma-Focused Cognitive Behavioral Therapy (TF-CBT)	Treatment that involves reducing negative emotional and behavioral responses related to trauma by providing psychoeducation on trauma, addressing distorted beliefs and attributes related to trauma, introducing relaxation and stress management techniques, and developing a trauma narrative in a supportive environment.
What Seems to Work	
School-based Group Cognitive Behavioral Therapy (CBT)	Similar components to TF-CBT, but in a group, school-based format.

# POST-TRAUMATIC STRESS DISORDER (CONT.)

Not Adequately Tested	
Child-centered Play Therapy	Therapy that utilizes child-centered play to encourage expression of feelings and healing.
Psychological Debriefing	An approach in which youth talk about the facts of the trauma (and associated thoughts and feelings) and then are encouraged to re-enter into the present.
Pharmacological Treatments	Treatment with selective serotonin reuptake inhibitors (SSRIs).
Peer Treatment	Classroom treatment that pairs withdrawn children with resilient peers with a parent present for assistance.
Eye Movement Desensitization and Reprocessing Therapy (EMDR)	Therapy that utilizes visual and physical memory imagery while the clinician creates visual or auditory stimulus to reduce negative memory and increase positive memory.
What Does Not Work	
Restrictive rebirthing or holding techniques	Restrictive rebirthing or holding techniques that may forcibly bind or restrict, coerce, or withhold food/water from children and have resulted, in some cases, in death; not recommended.

## **SCHIZOPHRENIA**

What Works	
There are no evidence-based practices at this time.	
What Seems to Work	
Psychopharmacological treatment with second- generation (atypical) antipsychotics	Risperidone Aripiprazole Quetiapine Paliperidone Olanzapine
Psychopharmacological treatment with traditional neuroleptics/first generation antipsychotics	Molindone Haloperidol
Family psychoeducation and support	Helps to improve family functioning, problem solving and communication skills, and decrease relapse rates.
Cognitive behavioral therapy (CBT)	Includes social skills training, problem-solving strategies, and self-help skills.
Cognitive remediation	Pointed tasks to help improve specific deficiencies in cognitive, emotional, or social aspects of a patient's life.
Not Adequately Tested	
Electroconvulsive therapy (ECT)	Small electric currents are passed through the brain, intentionally triggering a brief seizure to reverse symptoms of certain mental illnesses. Unproven as effective in youth. Should only be used as a last effort after all risks are weighted against possible benefits.
What Does Not Work	
Psychodynamic therapies	Talk therapies that focus on a client's self-awareness and understanding of the influence of the past on present behavior. These therapies are considered to be potentially harmful for youth with schizophrenia.

## **SEXUAL OFFENDING**

What Works	
There are no evidence-based practices at this time.	
What Seems to Work	
Multisystemic therapy for problem sexual behaviors (MST-PSB)	An intensive family- and community-based treatment that addresses the multiple factors of serious antisocial behavior in juvenile sexual abusers.
Cognitive behavioral therapy (CBT) Children with problematic sexual behavior CBT (PBS-CBT)	Treatment modalities that provide cognitive-behavioral, psychoeducational, and supportive services.
Not Adequately Tested	
Pharmacological treatment	There is no research validation for the use of medication targeting sexually deviant behavior in youth and only limited methodologically sound research to guide in the treatment of adults.

# SUBSTANCE USE DISORDERS

What Works	
Cognitive behavioral therapy (CBT)	A structured therapeutic approach that involves teaching youth about the thought-behavior link and working with them to modify their thinking patterns in a way that will lead to more adaptive behavior in challenging situations.
Family therapy Multidimensional family therapy (MDFT) Functional family therapy (FFT)	Family-based therapy is aimed at providing education, improving communication and functioning among family members, and reestablishing parental influence through parent management training. MDFT views drug use in terms of networks of influences (individual, family, peer, community) and encourages treatment across settings in multiple ways. FFT is best used in youth with conduct and delinquent behaviors along with substance use disorders combining relationship with CBT interventions to change relationship patterns and improve the family's functioning.
Multisystemic therapy (MST)	An integrative, family-based treatment with a focus on improving psychosocial functioning for youth and families.
What Seems to Work	
Behavioral therapies	Behavioral therapies focus on identifying specific problems and areas of deficit and working on improving these behaviors.
Motivational interviewing (MI)  Motivational enhancement therapy (MET)	MI is a brief treatment approach aimed at increasing motivation for behavior change. It is focused on expressing empathy, avoiding argumentation, rolling with resistance, and supporting self-efficacy. MET is an adaptation of MI that includes one or more client feedback sessions in which normative feedback is presented and discussed.
Pharmacological treatments	Some medication can be used for detoxification purposes, as directed by a doctor. Medication may also be used to treat co-existing mental health disorders.

# SUBSTANCE USE DISORDERS (CONT.)

Not Adequately Tested	
Multifamily educational intervention (MEI)	MEI combines psycho-educational and family interventions for troubled adolescents and their families.
Adolescent group therapy (AGT)	The AGT intervention incorporates adolescent therapy groups on stress management, developing social skills, and building group social support.
Interpersonal and psychodynamic therapies	Interpersonal and psychodynamic therapies are methods of individual counseling that are often incorporated into the treatment plan and focus on unconscious psychological conflicts, distortions, and faulty learning.
Client-centered therapies	A type of therapy focused on creating a non-judgmental environment, such that the therapist provides empathy and unconditional positive regard. This facilitates change and solution making on behalf of the youth.
Psychoeducation	Programs aimed at educating youth on substance use and may cover topics like peer pressure and consequences of substance use.
Project CARE	A program aimed at raising awareness about chemical dependency among youth through education and training.
Twelve-step programs	A twelve-step program that uses the steps of Alcoholics Anonymous as principles for recovery and treating addictive behaviors.
Process groups	A type of psychotherapy that is conducted in a small group setting. Groups can be specialized for specific purposes and therapy utilizes the group as a mechanism of change.

## TRICHOTILLOMANIA (HAIR PULLING DISORDER) AND EXCORIATION (SKIN PICKING DISORDER)

What Works		
There are no evidence-based practices at this time.		
What Seems to Work		
Habit reversal therapy (HRT)	Treatment increases awareness to the feelings and context associated with the urges and implements a competing and inconspicuous habit in place of the hair pulling and skin picking.	
Cognitive behavioral therapy (CBT) for trichotillomania	Treatment involves exposing children to the stimuli associated with the urge, while challenging thoughts associated with high-risk situations.	
Not Adequately Tested		
SSRIs N-acetylcysteine Naltrexone	Some demonstrated improvement on certain measures of picking behavior has been demonstrated in some pharmacological studies.	

## YOUTH SUICIDE

What Works		
Currently no psychopharmacological treatments meet criteria for a treatment that works.		
Currently no psychological treatments meet criteria for a treatment that works.		
What Seems to Work		
Selective serotonin reuptake inhibitors (SSRIs)	These antidepressants may help reduce suicidal ideation; however, in some individuals they may cause suicidal ideation. Youth taking SSRIs must be closely monitored.	
Cognitive behavioral therapy (CBT) Dialectical behavior therapy (DBT)	These psychotherapies have both shown promise in reducing suicidal ideation in some youth when paired with appropriate medication therapy. Other psychotherapies, such as interpersonal therapy for adolescents, psychodynamic therapy, and family therapy, may also be effective.	
SOS Signs of Suicide Prevention Program	A school-based education and screening program that teaches students to recognize warning signs of depression and suicidality in themselves or their peers.	
Not Adequately Tested		
Gatekeeper training	Involves educating youth, parents, and caregivers in warning signs of suicide to encourage early intervention.	
What Does Not Work		
Tricyclic antidepressants	Not recommended; effectiveness has not been demonstrated, and older tricyclic antidepressants are lethal in overdose quantities.	
No-suicide contracts	Designed as an assessment tool, not a prevention tool. Studies on effectiveness in reducing suicide are inconclusive and their use is discouraged, as they may be interpreted as being coercive or may encourage suicide in some individuals.	

# EURODEVELOPMENTAL DISORDERS

Introduction

Developmental Disabilities

Co-occurrence of Mental Health Disorders and Developmental Disabilities

#### Introduction

In 2013, the American Psychiatric Association (APA) released the fifth edition of the *Diagnostic* and *Statistical Manual of Mental Disorders* (*DSM-5*), replacing the *Diagnostic and Statistical Manual Fourth Edition Text Revision* (*DSM-IV-TR*). In the *DSM-5*, the section, "Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence" was replaced with a new section, "Neurodevelopmental Disorders." This new *DSM-5* classification includes those neurodevelopmental disabilities that manifest early in development, often before the child enters grade school, and are characterized by developmental deficits that produce impairments of personal, social, academic, or occupational functioning (APA, 2013). The neurodevelopmental disorders discussed in the *Collection* include autism spectrum disorder (ASD), intellectual disability (ID), attention-deficit/hyperactivity disorder (ADHD), and motor disorders.

## **Developmental Disabilities**

Developmental disabilities, as defined by the Centers for Disease Control (CDC), are a diverse group of severe chronic conditions that cause mental and/or physical impairments. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime. Individuals with developmental disabilities have substantial limitations in three or more of the following areas:

- Self-care
- Comprehension and language
- Skills (receptive and expressive language)
- Learning
- Mobility
- Self-direction
- Capacity for independent living
- Economic self-sufficiency
- Ability to function independently without coordinated services (42 U.S.C. § 15002)

Developmental disability is an umbrella term that includes intellectual disorders (such as intellectual disability) and physical disorders (such as cerebral palsy and epilepsy) that occur during early childhood (American Association on Intellectual and Developmental Disabilities

(AAIDD), 2013). Some developmental disabilities include both a physical and intellectual component, such as Down syndrome or fetal alcohol syndrome.

Recent estimates in the United States show that about one in six, or about 15 percent, of children aged three through 17 years have one or more developmental disabilities (Boyle et al., 2011; CDC, 2017). The CDC and the U.S. Administration on Developmental Disabilities assert that 1.8 percent of the total general population have a developmental disability. Using this rate, it is estimated that there are 147,346 adults and children in Virginia with a developmental disability (Virginia Department of Behavioral Health and Developmental Services (VDBHDS), 2013). In December 2010, the Virginia Department of Education reported 8,244 children ages three to five were diagnosed with a developmental disability (VDBHDS).

Developmental disabilities require a combination and sequence of care, treatment, or other services of lifelong or extended duration. Service providers should keep in mind the diverse needs of individuals with developmental disorders and formulate goals to help them live more active, productive, and independent lives.

#### Co-occurrence of Mental Health Disorders and Developmental Disabilities

Youth with developmental disabilities may also have a diagnosable mental health disorder, also known as a dual diagnosis. While most professionals understand dual diagnosis to describe those who suffer from both mental health disorders and substance abuse, the term is also used for those with the double challenge of a developmental disability and a mental health disorder (Hartwell-Walker, 2012). Clinicians who do not recognize the possibility of dual diagnosis may leave mental health issues untreated and exacerbate symptoms. A dual diagnosis may cause significant clinical impairment, placing an additional burden on youth with developmental disorders and their families.

The full range of psychopathology that exists in the general population can also co-exist in youth who are diagnosed with developmental disabilities (Davis, Jivanjee, & Koroloff, 2010). Youth of all ages and levels of functioning can receive a dual diagnosis. Estimates of the frequency of dual diagnosis vary widely; however, many professionals estimate 30 to 35 percent of all individuals with a developmental disability also have a mental health disorder (Fletcher, as cited by Davis, Jivanjee, & Koroloff).

There are several notable limitations to studies that assess the incidence or prevalence of cooccurring mental health and developmental disabilities:

- The technology for assessing mental health disorders in youth with developmental disabilities is not yet well developed (Davis, Jivanjee, & Koroloff, 2010).
- Assessment may be affected by "diagnostic overshadowing," which can occur when symptoms of a mental health disorder are "overshadowed" by the presence of a diagnosed developmental disability and the behavior is believed to be a result of the developmental disability (Reiss, Levitan, & Szyszko, as cited by Davis, Jivanjee, & Koroloff).

• Variability in the way that developmental disabilities and mental health disorders are defined makes it difficult to obtain reliable estimates of dual disorders. Clinicians or service providers who assign a primary diagnosis of the developmental disability could possibly ignore the mental health disorder (NADD, n.d.).

VDBHDS has noted an increasing demand by individuals with both co-occurring mental health disorders and developmental disabilities for services for specialized interventions and care (VDBHDS, 2012). Moreover, youth with co-occurring developmental disabilities and mental health disorders may not be identified, and when they are, their needs are frequently overlooked. The co-existence of developmental disabilities and mental health disorders can have serious effects on the youth's daily functioning by interfering with educational and vocational activities and by disrupting family and peer relationships. The presence of a mental health disorder can greatly reduce the quality of life of a youth with a developmental disability, making it important that accurate diagnosis and appropriate treatment be obtained.

Service providers may use structured or semi-structured tools developed for individuals with developmental disabilities to improve the accuracy of the mental health diagnosis. A full psychiatric/behavioral assessment for youth with developmental disability is a critical step to help accurately diagnose a co-occurring mental health disorder.

The *Collection* provides an updated listing of evidence-based practices for children and adolescents with neurodevelopmental disorders and mental health disorders. The *Collection* is for parents, caregivers, educators, service providers and others seeking current research. It provides information that represents the medical model, the traditional approach to the diagnosis and treatment of medical conditions. This model focuses on the physical and biological aspects of specific diseases and conditions.

It is important to note that the medical model does not focus on the holistic needs of the individual; instead, it is the role of the service provider to use a problem-solving approach to address these needs. For example, the medical model does not incorporate changes in the language or methods used for communicating and interacting with individuals with developmental disabilities. A service provider, on the other hand, can use "person-centered" planning and approaches that addresses these needs while focusing on other emotional and support needs. Person-centered practices promote individualized treatment and service plans and emphasize individualized outcomes and the participation of the individual in their treatment planning. Furthermore, these plans focus on the services needed for the youth to address his or her mental health disorder and to lead successful integrated lives in their community (National Association of State Mental Health Program Directors, 2004).

#### **Resources and Organizations**

## Administration on Intellectual and Developmental Disabilities (AIDD)

501 3rd Street, NW Suite 200 Washington, D.C. 20001 202-387-1968 http://www.aamr.org/

#### **Centers for Disease Control and Prevention**

National Center on Birth Defects and Developmental Disabilities
Division of Birth Defects and Developmental Disabilities
1600 Clifton Road MS E-87
Atlanta, GA 30333
800-CDC-INFO (800-232-4636)
888-232-6348 (TTY)

https://www.cdc.gov/ncbddd/index.html

## **Center for Excellence in Developmental Disabilities (CEDD)**

2825 50th Street
Sacramento, CA 95817
916-703-0280
http://ucdmc.ucdavis.edu/mindinstitute/centers/cedd.html

#### **Center for Parent Information and Resources (CPIR)**

c/o Statewide Parent Advocacy Network 35 Halsey St., Fourth Floor Newark, NJ 07102 http://www.parentcenterhub.org/

#### **National Association of the Dually Diagnosed (NADD)**

132 Fair Street Kingston, NY 12401 845-331-4336 800-331-5362 http://thenadd.org/

## **Virginia Resources and Organizations**

## disAbility Law Center of Virginia (dLCV)

(formerly the Virginia Office of Protection and Advocacy)
1512 Willow Lawn Drive, Suite 100
Richmond, Virginia 23230
800-552-3962

http://dlcv.org/

#### Partnership for People with Disabilities

Virginia University Center of Excellence Virginia Commonwealth University P.O. Box 843020

Richmond, VA 23284-3020 804-828-3876; 800-828-1120; 804-828-0042

https://partnership.vcu.edu/

## Virginia Board for People with Disabilities

1100 Bank St., 7<sup>th</sup> Floor, Washington Office Bldg. Richmond, VA 23219 804-786-0016; 800-846-4464

https://www.vaboard.org/

#### Virginia Department for Aging and Rehabilitative Services

8004 Franklin Farms Drive Henrico, VA 23229-5019

804-662-7000; Toll Free 800-552-5019

Toll Free TTY: 800-464-9950

https://vadars.org/

#### Virginia Department of Behavioral Health and Developmental Services

Office of Developmental Services

P.O. Box 1797 – Richmond, VA 23219

804-786-1746 or 800-371-8977; 804-786-1587 (V/TTY)

http://www.dbhds.virginia.gov/

#### Virginia Department of Education

Office of Special Education and Student Services

P.O. Box 2120 - Richmond, VA 23218-2120

804-225-2402

http://www.doe.virginia.gov/special\_ed/index.shtml

#### Virginia Department of Health

Child & Adolescent Health, Division of Child & Adolescent Health 109 Governor Street, 8<sup>th</sup> Floor – Richmond, VA 23219 804-864-7685 http://www.vdh.virginia.gov

## Virginia Department of Medical Assistance Service

600 East Broad Street – Richmond, VA 23219 804-786-7933 http://www.vdh.virginia.gov/

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# NTELLECTUAL DISABILITY

#### Introduction

Recent Changes from the DSM-IV to the DSM-5

**Prevalence** 

**Assessment and Diagnosis** 

**Causes and Risk Factors** 

Intellectual Disability and Co-occurring Mental Health Disorders

Interventions

**Behavioral Interventions** 

Behavioral Interventions in Dual Diagnosis

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Discharge Planning

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#### Introduction

Intellectual disability is defined as any disorder with an onset during the developmental period that limits both the intellectual and adaptive functioning of a child (American Association on Intellectual and Developmental Disability [AAIDD], 2013). Adaptive functioning includes the conceptual, social, and practical domains of a child's development (American Psychiatric Association [APA], 2013). A limit to adaptive functioning can be any deficit wherein a youth has difficulty adjusting to different environments or specific tasks compared to their peers (AAIDD). Deficits in any of the following could be present:

- <u>Conceptual skills:</u> language, reading, writing, math, memory, reasoning, and knowledge
- <u>Social skills:</u> empathy, social judgment, interpersonal communication skills, ability to make and keep friends
- <u>Practical skills:</u> self-management (job responsibilities, money management, personal care, and school tasks) (APA, 2013b)

In recent years, there has been an effort to replace the term "mental retardation" with the term "intellectual disability" (AAIDD, 2007). The Centers for Disease Control has made this change,

as has the AAIDD. In addition, the President's Committee on Mental Retardation has also adopted the change and renamed the committee the President's Committee for People with Intellectual Disabilities (PCPID). The *DSM-5* also reflects the change by using the term intellectual disability instead of mental retardation (APA, 2013a).

Virginia has also taken steps to replace the term mental retardation with intellectual disability. In 2008, the Virginia General Assembly passed legislation to rename Virginia's Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) to the Virginia Department of Behavioral Health and Developmental Services (VDBHDS). The final version of the bill required that it also be passed by the 2009 General Assembly before becoming effective. The 2009 General Assembly unanimously approved the new name. The Board of VDBHDS and the Office of the Inspector General were re-named to reflect this change. This measure was adopted to support the Department's mission and to move away from the stigma associated with the term mental retardation. To this end, in 2012, the Virginia General Assembly passed legislation (House Bill 552, Garrett; Senate Bill 387, Martin) eliminating the term mental retardation in the *Code of Virginia* and replacing it with intellectual disability.

Children with an intellectual disability may also have a diagnosable mental health disorder. This is known as a dual diagnosis. While most professionals understand dual diagnosis to describe those who suffer from both mental health disorders and substance abuse, the term is also used for those with the double challenge of intellectual disability and a mental health disorder (Hartwell-Walker, 2012). A dual diagnosis may cause significant clinical impairment in youth with intellectual disability and place additional burden upon these youth and their families. Unfortunately, it is frequently assumed that behaviors associated with co-occurring disorders are related to the intellectual disability. Holding to this assumption can leave mental health issues untreated and exacerbate symptoms.

At its November 9, 2011, meeting, the Commission on Youth recommended that the *Collection's* section on Intellectual Disability be revised to include discussion of co-occurring mental health disorders. Accordingly, this revised section includes additional information about intellectual disability, as well as commonly co-occurring mental health disorders.

## Recent Changes from the DSM-IV to the DSM-5

In 2013, the American Psychiatric Association released the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. Several key changes were made to the intellectual disability category. The *DSM-5* is a manual for assessment and diagnosis of mental health disorders and does not include information for treatment of any disorder (APA, 2013a).

As noted previously, the *DSM-5* replaces the term "mental retardation" (which was used in the *DSM-IV*) with the term "intellectual disability." Intellectual disability is now the accepted term in medical, educational, and other professional realms (APA, 2013a). The *DSM-5* also outlines new diagnostic criteria for clinicians. Adaptive functioning assessments must be used in conjunction with intelligence quotient (IQ) scores instead of using IQ scores as the sole determinant of intellectual disabilities, and severity must be determined through adaptive functioning assessments alone, instead of IQ scores (APA). By removing IQ scores from the severity portion of diagnosis, an overemphasis on scores is eliminated and the individual's overall functioning

level is emphasized. IQ scores are still to be used in the assessment for intellectual disabilities. Intellectual disability is considered anything two standard deviations or more below the mean of the population; which is the equivalent of an IQ score of about a 70 or below (APA 2013b).

In the future, more evidence supporting treatments of disorders with *DSM-5* classifications will be available as clinical studies utilizing *DSM-5* criteria are conducted. As a result, this *Collection* will reference studies that utilize *DSM-IV* diagnostic criteria to explain symptoms and treatments.

#### **Prevalence**

Estimates of the prevalence of intellectual disability vary, depending on a number of factors including diagnostic criteria, study design, and methods of ascertainment. Intellectual disability affects about 1.5 to 2.5 percent of the population (Bethesda Institute, 2012) and about 1 in 10 families in the United States (AAIDD, 2007). Cases of severe intellectual disability occur in less than one percent of the general population (APA, 2013a).

The following information is specific to Virginia. Using national prevalence rates from studies and surveys, VDBHDS estimates that in 2012 approximately 76,763 individuals six years old and older in Virginia had an intellectual disability and 15,626 children received developmental services through Infant and Toddler Connection (VDBHDS, 2013).

## **Assessment and Diagnosis**

A multidisciplinary team, which may include psychologists, psychiatrists, pediatricians, and clinical geneticists, typically conducts the assessment for intellectual disability. All assessments should be comprehensive and should include standardized testing of intellectual ability, adaptive behavior, adaptive function, and detailed family and medical history evaluation (AACAP, 1999; APA, 2013a).

The *DSM-5* provides the standard criteria for a diagnosis of intellectual disability used in diagnosis of both children and adults (APA, 2013a). The disorder is characterized by:

- Deficits in intellectual functioning;
- Significant limitations in adaptive functioning; and
- Onset before the age of 18 (APA).

#### Intellectual Functioning

Intellectual functioning is typically measured by individually administered cognitive assessment instruments (AACAP, 1999; AAIDD, 2007). According to the AACAP and the *DSM-5*, clinicians must consider the socio-cultural background and native language of the youth when choosing a cognitive assessment instrument. Ignoring these variables may lead to a falsely positive diagnosis of intellectual disability in youth of linguistic and cultural minorities. For a diagnosis of intellectual disability, the youth must have an IQ that falls below 70, or two standard deviations below the mean of the population (APA, 2013b).

## Adaptive Functioning

Adaptive behavior refers to an individual's effectiveness in functioning at an age and culturally appropriate level compared to his or her peers (APA, 2013a). The *DSM-5* uses adaptive functioning assessments to determine the severity of intellectual disability instead of IQ scores. This change bolsters the importance of careful assessment in this criterion. Table 1 lists the three domains of adaptive functioning as discussed in the *DSM-5*.

Table 1

Adaptive Functioning Domains

Domain	Life Skills Affecting Adaptive Functioning
Conceptual	Comprises academic competencies, including language, memory, reading and writing, math, practical skills and problem solving, and judgment in new situations and around others
Social	Emphasizes skills including awareness of the thoughts and feelings of others, empathy, interpersonal communication, friendship, and social judgment
Practical	Life skills like practicality, managing oneself, personal care, job expectations, managing money, recreation, and school organization

Source: APA, 2013a.

A youth must have significant deficits in one of three domains that are so great they require ongoing support and care in order for the child to go to school or to be a contributing member of society. While these deficits are within the realm of adaptive functioning, they must be paired with intellectual functioning deficits to be considered a true intellectual disability (APA, 2013a). Table 2 outlines the varying degrees of severity for intellectual disability.

Table 2
Intellectual Disability Severity

Severity	Description
Mild	<ul> <li>Majority of individuals with intellectual disability</li> <li>Able to achieve nominal academic gains</li> <li>Mostly self-sufficient</li> </ul>
Moderate	<ul> <li>Around 10 percent of intellectual disability population</li> <li>Adequate, but limited, communication skills</li> <li>Self-care possible with assistance or extensive instruction</li> <li>Independence possible with support system</li> </ul>
Severe	<ul> <li>Around 3 to 4 percent of the intellectual disability population</li> <li>Basic communication skills</li> <li>Require safety supervision and supportive assistance</li> </ul>
Profound	<ul> <li>Around 1 to 2 percent of intellectual disability population</li> <li>24-hour care and support</li> <li>Co-occurring sensory/ physical limitations</li> </ul>

Source: Reynolds, Zupanick, & Dombeck, n.d.

#### Age of Onset

The *DSM*-5 also stipulates that the onset of symptoms occur during the developmental period (APA, 2013a). This does not prohibit diagnosis of a person after the age of 18. Rather, there must be documented evidence that the onset of symptoms occurred prior to the age of 18. It is important to note, however, that children under age 2 should not be given a diagnosis of intellectual disability unless the deficits are relatively severe and/or the child has a condition that is highly correlated with intellectual disability, such as Down syndrome (APA). Prior to age two, service providers should acknowledge any cognitive or behavioral deficit as a form of developmental disability and leave room for further diagnosis as the child gets older, unless the deficits are relatively severe (Biasini, Grupe, Huffman & Bray, 1992).

#### **Causes and Risk Factors**

Knowledge of the causes of intellectual disability in a particular case is important for a number of reasons because the cause may be associated with a particular "behavioral phenotype" or increased risk for a medical disorder. In the general population, doctors can find a specific reason for an intellectual disability in 25 percent of cases (National Library of Medicine [NLM], 2015). However, in 58 to 78 percent of youth with mild intellectual disability, and in 23 to 43 percent of youth with severe intellectual disability, no causation is ascertained with current diagnostic techniques (AACAP, 1999). In other cases, numerous causes of intellectual disability have been identified. In general, the milder the severity of intellectual disability, the more difficult it is to identify the etiology (Jellinek, Patel & Froehle, 2002). The following are risk factors associated with the development of intellectual disability:

- Infections (present before or shortly after birth)
- Chromosomal abnormalities (e.g. Down syndrome)
- Environmental factors
- Nutritional (e.g. malnutrition)
- Toxic exposure (exposure to alcohol, cocaine, amphetamines, and other drugs)
- Trauma (present before or shortly after birth) (NLM)

#### **Intellectual Disability and Co-occurring Mental Health Disorders**

Youth with intellectual disability are significantly more likely to be diagnosed with a comorbid disorder (APA, 2013a). It is estimated that between 32 and 40 percent of all individuals with intellectual disability also have another serious mental health disorder. Specific disorders include attention-deficit/hyperactivity disorder (ADHD), major depressive disorder, autism spectrum disorder, schizophrenia, bipolar disorder, and anxiety disorders (Aggarwal, Guanci, & Appareddy, 2013). Furthermore, assessment for these comorbid disorders is extremely difficult due to the preexisting intellectual disability. Assessments may have to be altered in order to properly overcome communication barriers and motor/sensory deficits (APA). Clinicians note that these challenges make it difficult to diagnose mental health disorders in individuals with intellectual disability.

Specifically regarding youth, a study was conducted with a large, nationally representative sample of British children with and without intellectual disability to ascertain the relationship

between mental health disorders and intellectual disability (Emerson & Hatton, 2007). The results of the study indicated that the prevalence of a wide range of mental health disorders was significantly higher among children with intellectual disability. This study was conducted on a combined sample of 18,415 children and revealed that the prevalence of psychiatric disorders was 36 percent among children with intellectual disability versus 8 percent among children without (Emerson & Hatton). This study found the prevalence rates of psychiatric disorders for children and adolescents with intellectual disabilities to be higher among children with intellectual disabilities for 27 of 28 comparisons and statistically significantly elevated for 20 of the 28 comparisons. Additionally, increased prevalence rates were marked for ADHD and conduct disorders, with the latter accounting for approximately two-thirds of all diagnoses among children with intellectual disability. The study also noted that there was a cumulative risk of exposure to social disadvantage with increased prevalence rates for any mental health disorder, including any conduct disorder and ADHD, for children with and without intellectual disability. Social disadvantage may include the adverse impact on education, employment, earnings, and increased expenditures related to disability (World Health Organization, 2011). Children with intellectual disability were at significantly greater risk of exposure to all forms of social disadvantage that were examined.

This study contradicts the previously held belief among physicians that ADHD did not occur in children with intellectual disability. As a result of this belief, treatments for ADHD, including stimulant medications, were rarely used to treat children with intellectual disability and ADHD. However, recent research reveals that as many as 25 to 40 percent of children with intellectual disability also have ADHD, significantly more than in the general population (American Academy of Pediatrics, 2012).

According to the *DSM-5*, the most prevalent co-occurring disorders are ADHD, depressive and bipolar disorders, anxiety disorders, and autism spectrum disorder. The *DSM-5* classifies ADHD and autism spectrum disorder as neurodevelopmental disorders due to the fact that these disorders typically manifest early in development and are characterized by developmental deficits that impair personal, social, academic, or occupational functioning (APA, 2013a). Major depressive disorder may occur in a wide range of individuals with intellectual disability. Furthermore, individuals with severe intellectual disability are more likely to exhibit aggression and disruptive behaviors (e.g., harm to self and others or property destruction) (APA). Table 3 lists co-occurring mental health disorders and their prevalence rates.

An accurate psychiatric diagnostic evaluation and diagnosis provide the foundation for effective treatment planning (Aggarwal, Guanci, & Appareddy, 2013). Such a psychiatric diagnostic evaluation would be sufficiently comprehensive to identify the child's disabilities and educational needs. Clinicians diagnosing co-occurring mental health disorders in children and adolescents with a severe intellectual disability may have to rely more on information obtained from family and other caregivers, including direct behavioral observations of the child in various settings. In general, the assessment of co-occurring mental health disorders in youth with intellectual disability should include the following, as adapted from AACAP:

1. Comprehensive history obtained from child, parents, teachers, and other caregivers across different settings (e.g., home and school). Such a comprehensive history must include information about: presenting symptoms with concrete behavioral examples, psychiatric

symptoms (e.g., premorbid and current behavioral and personality patterns), adaptive functioning, self-care, communication, social functioning, past psychiatric diagnoses and treatment history, past and current educational and rehabilitative programs history, past and current cognitive assessment results, and multiple perspectives on the child's presenting concerns.

- 2. Interview of the child that is tailored to the youth's needs and ability levels.
- 3. Medical review, including developmental and medical history, past treatments, and coexisting general medical conditions and their treatment and/or prognosis.
- 4. Diagnostic formulation that takes into account the youth's developmental level, communication skills, associated impairments, familial and socio-cultural factors, and possible abuse.

Table 3

Prevalence of Co-occurring Mental Health/Neurodevelopmental Disorders Among
Children and Adolescents with or without Intellectual Disability

Co-occurring Disorder	Prevalence Rates by Percentage (Percentage children/adolescents with the disability or disorder at a particular time)	
	With Intellectual Disability	Without Intellectual Disability
Any psychiatric disorder	36.0	8.0
Any emotional disorder	12.0	3.7
Any anxiety disorder	11.4	3.2
Any depressive disorder	1.4	0.9
Attention-deficit/hyperactivity disorder (ADHD)	8.3	0.9
Any conduct disorder	20.5	4.3
Autism spectrum disorder	8.0	0.3
Tic disorder	0.8	0.2
Eating disorder	0.2	0.1
Emotional disorder & conduct disorder	4.4	0.8
Conduct disorder & ADHD	5.8	0.6
Emotional disorder & ADHD	1.3	0.1
Emotional disorder & conduct disorder & ADHD	0.8	0.1

Source: Emerson & Hatton, 2007.

Many treatment modalities and interventions have been tried, with varying degrees of effectiveness, with youth with intellectual disability and co-occurring mental health disorders (NADD, n.d.). It is considered best practice to use evidence-based treatments. Please refer to the appropriate sections of the *Collection* for additional information on evidence-based and promising treatments for the mental health disorders discussed in this section.

#### Interventions

An array of therapeutic techniques can be employed to treat mental health disorders in youth with intellectual disability. Of these, the most widely utilized and investigated have been behavioral interventions, psychopharmacological interventions, and environmentally mediated interventions, which include developmental and educational services. Individual, group, and/or family psychotherapy may also be included in the treatment plan. Verbal psychotherapies are most appropriate for persons with mild to moderate intellectual disability.

Effective interventions for children and adolescents with intellectual disability should contribute to improving quality of life. According to the AACAP (1999), these interventions are based on several guiding principles: person-centered planning, appropriate education, family training, community integration, and transition planning for adulthood.

Table 4 summarizes interventions for youth with intellectual disability.

Table 4
Summary of Interventions for Youth with Intellectual Disability

What Works			
Behavioral interventions, such as positive behavior support (PBS)	Behavioral interventions analyze the cause of a negative behavior and how it is being reinforced, and then offer techniques targeted to promoting positive behaviors.		
What Seems to Work			
Psychotropic medication for co- occurring mental health disorders	Prescribed to treat comorbid disorders such as anxiety disorders, ADHD, and so forth. Because these medications have not been studied in ID populations, they should only be used when therapeutic and social measures do not properly address symptoms and in conjunction with appropriate behavioral interventions.		
Not Adequately Tested			
Psychotropic medications to treat challenging behaviors	Psychotropic medications are sometimes used "off label" to treat challenging behaviors such as aggression. These medications should be used with caution and only when necessary. They should never be used for the convenience of caregivers.		

#### Behavioral Interventions

Research conducted over the past 20 years has supported the effectiveness of behavioral interventions, including interventions using applied behavior analysis, in managing many of the challenges faced by children and adolescents with intellectual disability (King, State & Maerlender, 2005). Behavioral interventions are designed to provide alternatives to unwanted behaviors. These interventions analyze the cause of the behavior (antecedent) and how it is being reinforced. Techniques such as functional communication training (e.g., learning how to request breaks), noncontingent reinforcement (i.e., reinforcement delivered on a fixed time schedule), and extinction are used to reduce challenging behaviors (e.g., aggression, self-injury, task-avoidance) and to promote positive behaviors. Behavioral techniques target skills, deficits, and modifications to the individual's environment and are most effective if applied across multiple settings to promote generalization of skills.

There are many simple behavioral techniques that can be helpful in attempting to ease the transition of an individual with intellectual disability into the general public. The following are just a few examples:

- Setting boundaries
- Positive reinforcement of desired behaviors
- Activity schedules
- Task correspondence training (Aggarwal, Guanci, & Appareddy, 2013)

One behavioral intervention frequently used with youth with intellectual disability is positive behavior support (PBS). PBS is an approach to developing effective and individualized interventions for children with severe challenging behavior. PBS is a process for understanding and resolving the problem behavior of youth that was developed both from the science of applied behavior analysis and the values of child-centered approaches to learning (Fox & Duda, 2011). It offers an approach for developing an understanding of why the child engages in problem behavior and strategies for preventing the occurrence of problem behavior while teaching the child new skills. PBS considers all factors that impact a child and the child's behavior and can be used to address problem behaviors that range from aggression, tantrums, and property destruction to social withdrawal (Fox & Duda). It has three primary features: functional (behavioral) assessment, comprehensive intervention, and lifestyle enhancement. A functional literature review found that positive behavior support appeared to be effective in a majority of cases studied, although no long-term quality of life outcomes were reported.

# Behavioral Interventions in Dual Diagnosis

There is no single "best" treatment for youth with a co-occurring mental health disorder (King, State & Maerlender, 2005). Multimodal approaches seem to be the most effective form of treatment as they treat symptoms or the root problem in different ways (Aggarwal, Guanci, & Appareddy, 2013). An underlying assumption in treating co-occurring disorders in youth with intellectual disability is that most youth experience the same complex interaction of biological, mental health, and environmental forces that shape mental health disorders (King, State & Maerlender). It is critical that clinicians serving youth with both intellectual disability and co-

occurring mental health disorder use a comprehensive, multidimensional, and multidisciplinary approach.

Most service providers agree that treatment of dual disorders must include a comprehensive plan comprised of four components (National Association of the Dually Diagnosed [NADD], n.d.). The first component includes interdisciplinary evaluation of the youth, as noted in previous sections, in order to obtain an accurate diagnosis and to establish habilitation and treatment needs. The second is a thorough medical and neurological evaluation to identify acute or chronic conditions that need attention. The third component consists of a psychiatric evaluation to determine if medication is appropriate. Finally, follow-up interviews are crucial to help monitor the youth's response to the selected treatment approaches (NADD).

Functional behavioral assessments and positive behavior support (PBS) are widely considered best practices when teaching individuals with intellectual disabilities (Hansen, Wills, & Kamps, 2014). A functional behavioral assessment looks beyond the behavior itself and identifies specific social, affective, cognitive, and/or environmental factors associated with specific behaviors to offer a better understanding of the function or purpose behind student behavior (Center for Effective Collaboration and Practice, 2001). PBS is frequently used with children who persist in challenging behavior and do not respond to general child guidance procedures (Center on the Social and Emotional Foundations for Early Learning [CSEFEL], n.d.). In PBS, interventions are designed based on understanding the purpose of the challenging behavior. The positive strategies used to change behavior include teaching new skills, preventing the occurrence of challenging behavior, and supporting the child in achieving meaningful, long-term outcomes.

# Pharmacological Interventions

There are no pharmacological treatments available for intellectual disability (Zeldin et al., 2016). For this reason, psychotropic drugs should only be used to target co-occurring mental health disorders, and only when therapeutic and social measures do not properly address symptoms (Zeldin et al.; Aggarwal, Guanci, & Appareddy, 2013).

Reports of the prevalence of psychotropic medication use in both adults and children with intellectual disability show that over one-third of this population served in residential settings is receiving at least one psychotropic drug (Toth & King, 2010). Psychotropic medications are also used "off-label" for the treatment of challenging behaviors, such as aggression and behavioral disturbance (Toth & King). Clinicians have found that medication is often prescribed to children with intellectual disability for symptom suppression without being integrated into the overall plan (AACAP, 1999). The literature repeatedly advises that medication should not be used for the convenience of caregivers or as a substitute for appropriate services. An additional concern is that follow-up behavioral data is infrequently collected and providers often fail to monitor for side effects. This is especially important in children and adolescents with intellectual disability, because these patients may be unable to report side effect symptoms adequately.

## Pharmacological Interventions in Dual Diagnosis

As noted by the National Association of the Dually Diagnosed (NADD), in people with intellectual disabilities, medication is appropriate when there is a dual diagnosis for many psychiatric disorders, such as mood disorders and psychotic disorders. Medication treatment should not be a total treatment approach but rather be part of a comprehensive bio-psycho-social-developmental treatment approach. It is also important to note that the same rules for utilizing pharmacological interventions for children with a diagnosed mental health disorder apply to youth with intellectual disability (Toth & King, 2010).

In general, the effects of medication on children with intellectual disability are similar to that expected for the general population (King, State & Maerlender, 2005). However, treating ADHD with medication is contraindicated in youth with IQs less than 50, as pharmacological treatment can cause serious side effects such as tics, social withdrawal, irritability, and anxiety (Aggarwal, Guanci, & Appareddy, 2013).

Psychotropic drugs are also sometimes prescribed off label to treat children or adolescents who exhibit behavioral disturbances, including self-injury, stereotyped behaviors (e.g., hand or finger twisting, or complex whole body movements) and aggression (AACAP, 1999; Aggarwal, Guanci, & Appareddy, 2013). A 2015 meta-analysis of 14 studies of the effects of antipsychotic medication in reducing challenging behavior among children with intellectual disabilities found that they appeared to be effective in the short term; however, the authors caution that further long-term, high-quality research on the safety and efficacy of these treatments is needed (McQuire et al., 2015). There has also been much debate about whether medications such as antipsychotics should be used to treat these behaviors (Maston, 2009; Sheehan et al., 2015). In addition, concerns have been raised about the safety of the use of antipsychotic medications in young people (Sheehan et al.). Although evidence exists for using psychotropic medication to treat challenging behaviors, careful monitoring of effectiveness and side effects is recommended (Edelsohn et al., 2014). For these reasons, clinicians should be cautious about prescribing medication off label to treat challenging behaviors in individuals in youth with intellectual disability and should give proper consideration to behavioral intervention alternatives (Edelsohn et al.; McQuire et al.).

When psychotropic medications are prescribed for co-occurring disorders or challenging behaviors, special attention must be paid to possible behavioral effects and to the child or adolescent's ability to reliably report possibly dangerous side effects (Silka & Hauser, 1997). Table 5 outlines some of the different pharmacological approaches and the different comorbid symptoms that each drug treats for individuals with intellectual disability.

Table 5

Pharmacological Treatments and Their Side Effects

Drug	Targeted Symptoms	Potential Side Effects	
Risperidone	Hyperactivity, irritability, aggression, and impulsivity	Hyperprolactinemia, weight gain, somnolence, and headaches	
Quetiapine	Aggression and hyperactivity	Sedation, weight gain, and paradoxical agitation	
Ziprasidone	Aggression and irritability	Dizziness, fever, and fast/uneven heartbeat	
Stimulants and nonstimulant atomoxetine	Symptoms of ADHD	In persons with an IQ less than 50, can cause tics, social withdrawal, irritability, anxiety, and anorexia	
Fluoxetine	Stereotypic and self-injurious behaviors	Restlessness, hyperactivity, agitation, decreased appetite, insomnia	
Valproic acid	Aggression and self-injurious behavior	Hepatic failure, pancreatitis, thrombocytopenia, development of ovarian cysts, obesity, irregular menses, increased hair growth, sedation, GI upset, tremor, alopecia	

Source: Aggarwal, Guanci, & Appareddy, 2013.

# Discharge Planning

As indicated by Silka & Hauser (1997), appropriate discharge planning is crucial for children with intellectual disability and co-occurring mental health disorders who have received acute or short-term inpatient treatment. Ideally, discharge planning, including plans for outpatient follow-up and the provision of any additional services, should commence early in the process. Early and continual contact with all community supports, including family, school personnel, and outpatient therapists, is imperative.

Silka & Hauser (1997) outline three questions to be addressed by the treatment team:

- 1. What are the objectives?
- 2. Who is responsible for which service (case manager, family, agency, client, and others)?
- 3. What are the minimal discharge criteria?

# Developmental and Educational Services

The Individuals with Disabilities in Education Act (IDEA) (Public Law 94-142, Public Law 99-457, and Public Law 102-119) requires that children with intellectual disability or related developmental disorders receive a free and appropriate education (FAPE). The requirement for FAPE only applies to Part B educational services available from ages two to 22.

In Virginia, Part B preschool services are available to eligible children with disabilities from age two to age five (Virginia Board for People with Disabilities, 2014). While IDEA mandates that such services be available starting at age three, Virginia parents have the option of either IDEA Part B preschool or IDEA Part C early intervention services for their child between the ages of two and three. A separate eligibility determination is required for Part B services from that required for Part C.

Early intervention services under Part C are based on a multi-disciplinary evaluation and each state develops its own definition of eligibility. In Virginia, children from birth to age three are eligible for Part C early intervention services if the child:

- Has a 25-percent developmental delay in one or more areas of development,
- Has atypical development, or
- Is diagnosed with a physical or mental condition that has a high probability of resulting in a developmental delay (Virginia Board for People with Disabilities, 2014).

In Virginia, the Virginia Department of Behavioral Health and Developmental Services (VDBHDS) is the lead agency that administers Part C of IDEA. Virginia's statewide early intervention system is called the Infant & Toddler Connection of Virginia. Infant and toddler services can be home-based, center-based, or a combination. To the maximum extent possible, early intervention services are to be provided in the child's natural environment. The nature of the services is determined based on an assessment of the child and the family priorities. The services that are provided in response to this plan may include the identification of appropriate assistive technology, intervention for sensory impairments, family counseling, parent training, health services, language services, health intervention, occupational therapy, physical therapy, speech therapy, case management, and transportation to services (Biasini et al., 1999).

The following information is taken from the Virginia Board for People with Disabilities (2014). Pursuant to IDEA, special education is defined as specially designed instruction, offered at no cost to the parent(s), that meets the unique needs of a child with a disability, including instruction conducted in a classroom, in the home, in hospitals, in institutions, and in other settings, and instruction in physical education. According to IDEA, "specially designed instruction" means adapting, as appropriate to the needs of an eligible child, the content, methodology, or delivery of instruction a) to address the unique needs of the child that result from the child's disability; and b) to ensure the child's access to the general curriculum, so the child can meet the educational standards that apply to all children within the jurisdiction of the public school division. There are numerous students with disabilities who do not require special education services through an Individualized Education Program (IEP) but may need accommodations to be successful. Examples of accommodations include: giving a student preferential seating, allowing more time for tests, having certain tests read aloud, allowing the use of a calculator, and so forth. These students may be eligible for a 504 plan under Section 4 of the amended Rehabilitation Act of 1973. The 504 plan is generally developed by a committee consisting of the student with the disability, if appropriate; one or more of the student's parents or guardians; one or more of the student's teachers; and the school's 504 coordinator. A 504 plan, which must be updated annually, documents the student's disability, his or her need for accommodations, and the set of specific accommodations that will be provided by the school.

#### Other Elements for Consideration

#### **Cultural Factors**

Any assessment of adaptive behavior focuses on how well children can function and maintain themselves independently and how well they meet the personal and social demands outlined for them by their cultures. Because various cultures may hold their own views regarding the level of functioning/skills expected of children of certain ages, clinicians must be culturally sensitive in diagnosing children with intellectual disability, with or without co-occurring mental health disorders. In addition, the sociocultural background and native language of the child should be considered in assessing intelligence and level of impairment (AACAP, 1999; Colorado Board of Education, 2013).

## Family Involvement

Service providers must make every effort to include the family in all aspects of planning and service delivery for children and adolescents with intellectual disability with or without co-occurring mental health disorders (Aggarwal, Guanci, & Appareddy, 2013). They must consider the level of knowledge and understanding of the family regarding the disability of the child, and they must also be sure that the family is sufficiently informed of all service options. If professionals fail to acknowledge parents as partners in the process, they run the risk of alienating them, resulting in a lack of interest or participation in necessary services (NLM, 2015). Thus, the knowledge and expertise that families already possess about their child and their child's strengths should be valued (Hodapp, DesJardin & Ricci, 2003). Families of children with less common genetic syndromes become the experts on their child's disorder, frequently being the only ones with experience or knowledge of a particular syndrome (Fidler & Hatton, as cited by Hodapp, DesJardin & Ricci).

#### Peer Interaction

Successful peer interactions can have significant benefits for youth with intellectual disability. Through social interactions, children and adolescents can learn and practice social skills, develop peer relationships, and receive needed support. Research has shown that increased social competence can positively affect academic achievement and quality of life (Carter & Hughs, 2005; Goldstein et al., 2002; Hartup, 1999, as cited by Toth & King, 2010). A recommended approach for youth with an intellectual disability combines such support-based approaches with skills-based strategies.

## Lifestyle Considerations

Pain caused by dental, dietary-related, or muscle soreness issues may be common in children with intellectual disability (Zeldin, et al., 2016). Parents, guardians, and family members can help physicians determine the source of pain and ensure proper pain management treatment.

## Availability of Community Services and Supports

The Arc, a non-profit organization that supports persons with intellectual disability, has reported that over 300,000 children and adults nationwide are on waiting lists for such essential supports

and services as service coordination, housing, employment, in-home supports, early intervention, transportation, and respite care (The Arc, 2017). A report by the VDBHDS (2013) shows that service availability for children with intellectual disability is also a serious concern in Virginia. In the 2014 – 2020 Comprehensive State Plan, VDBHDS reported that 611 children and adolescents were on the waiting list for intellectual disability services.

In Virginia, individuals with an intellectual disability may be eligible to receive services from Virginia's Medicaid Waivers. Medicaid Waivers are partnerships between the family support system and Medicaid providers to provide services that allow individuals with intellectual disability to live in their communities rather than reside and receive services in an institution. Virginia has six approved Waivers. Three of these Waivers, the Intellectual Disability (ID) Waiver, the Day Support for Persons with Intellectual Disabilities (DS) Waiver, and the Individual and Family Developmental Disabilities Support (DD) Waiver provide community based supports to individuals with intellectual disabilities.

Virginia's ID Waiver serves children and adults with an intellectual disability diagnosis and provides a variety of services. To be eligible for the ID Waiver, an individual must be six years of age or older and must have a psychological evaluation completed by a licensed professional that states a diagnosis of intellectual disability and reflects the individual's current level of functioning (VDBHDS & Virginia Department of Medical Assistance Services [VDMAS], 2015). The DD Waiver serves adults and children six years of age and up with developmental disability diagnosis who require home and community-based services to live in the community. Group residential services are not provided through this Waiver. Virginia also administers the Day Support Waiver, which provides services to individuals with intellectual disability who are on the waitlist for the ID Waiver. Services are not as comprehensive as those offered through the ID Waiver but day support, pre-vocational services, and supported employment service are provided to recipients on the waitlist. Unfortunately, for both the ID and DS Waivers, there are waiting lists. As with all Medicaid-funded services, there are also financial eligibility criteria.

Research indicates that lack of services can exacerbate the problems of youth with intellectual disability, as it may allow for an increase in the severity of the disability or learning delays (The Arc, 2010). Furthermore, lack of services may also lead to greater dependence and isolation, and a decrease in self-esteem and productivity. Consequently, providers and policy makers must make every effort to identify these children and provide them with necessary services to ensure that they become productive members of society.

#### **Overview for Families**

The term "mental retardation" has been replaced with "intellectual disability" (APA, 2013a). Furthermore, the determinant for assessing the severity of an intellectual disability has transitioned from solely IQ scores to an adaptive functioning assessment. In order for a youth to be diagnosed with intellectual disability, he or she must have an onset of symptoms during the developmental period, have an IQ significantly below average (usually 70 or below), and have significant deficits in adaptive functioning (APA).

A large percentage of children with intellectual disability have the ability to lead productive lives if proper treatment and care are given. These children do not require long term

hospitalization/institutionalization and can be members of their respective communities. For best results, a physician should evaluate a youth's overall physical and intellectual strengths and weaknesses and create a tailored plan to help with a successful integration at home, school, and the community. The following areas should be the focus of a physician's evaluation:

- Neurology
- Psychology/Psychiatry
- Educational needs
- Hearing, speech, and vision
- Physical therapy (AACAP, 2012)

Youth with intellectual disability are often aware that they are educationally behind their peers. This can cause withdrawal, anger, nervousness, or behavioral challenges. Older children may experience depression; however, some may lack the communication skills to express their feelings and therefore may not receive the help they need (AACAP, 2012). Early diagnosis and intervention are crucial to successful treatment of intellectual disabilities and any comorbid mental health disorders. Dual diagnosis treatment serves as the best tool for comorbid conditions because all symptomology is treated (Aggarwal, Guanci, & Appareddy, 2013).

Regardless of whether there are co-occurring mental health disorders in a child with an intellectual disability, the family is encouraged to meet with a child psychologist, who can set reasonable expectations for development, create a plan offering opportunities for success, and offer useful information to the youth and parents about the stresses of growing up with intellectual disability (AACAP).

## **Resources and Organizations**

#### **American Association of Intellectual and Development Disabilities**

(formerly the American Association on Mental Retardation)

http://aaidd.org/

#### **Center for Parent Information and Resources**

http://www.parentcenterhub.org/

### **Council for Exceptional Children**

Division on Developmental Disabilities

http://www.dddcec.org/

#### **Individuals with Disabilities Education Act (IDEA)**

http://idea.ed.gov/

## **National Down Syndrome Society (NDSS)**

http://www.ndss.org/

## **National Fragile X Foundation**

https://fragilex.org/

## **National Organization on Fetal Alcohol Syndrome**

https://www.nofas.org/

## **U.S. Department of Education**

Office of Special Education and Rehabilitative Services

https://www2.ed.gov/about/offices/list/osers/index.html?exp=5

### U.S. Department of Health and Human Services

Administration for Children and Families

https://www.acf.hhs.gov/

Administration for Community Living

https://www.acl.gov/news-and-events/latest-news/administration-intellectual-and-developmental-disabilities-announces

#### The Arc of the United States

(formerly the Association for Retarded Citizens)

http://www.thearc.org/

## **Virginia Resources and Organizations**

## Partnership for People with Disabilities at Virginia Commonwealth University

https://partnership.vcu.edu/

## Virginia Board for People with Disabilities

https://www.vaboard.org/

### Virginia Department of Behavioral Health and Developmental Services (VDBHS)

http://www.dbhds.virginia.gov/

## **Virginia Department of Education**

Office of Special Education

http://www.doe.virginia.gov/special\_ed/index.shtml

## Virginia Office for Protection and Advocacy

disABILITY Law Center

http://dlcv.org/

## The ARC of Virginia

https://thearcofva.org/

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# Autism Spectrum Disorder

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#### Introduction

Autism Spectrum Disorder (ASD) is a life-long developmental disability that is typically diagnosed during childhood. ASD is categorized as a spectrum because there is a great range of abilities and traits found in youth diagnosed with this disorder. Some youth exhibit mild symptoms and others have much more severe symptoms. Many can also be characterized as having scatter skills, in which individuals are strong in certain areas and weaker in others.

ASD is marked by two main characteristics: difficulty in relating to others and a fixed set of interests or repetitive behaviors (Kennedy & American Psychiatric Association [APA], 2015). Youth with ASD also tend to have other communication and social challenges, such as responding inappropriately in conversations, misreading nonverbal interactions, and having difficulty building friendships appropriate to their age (APA, 2013a). Additionally, youth diagnosed with ASD may be dependent on routines and highly sensitive to changes in their environments.

In 2013, the American Psychiatric Association released the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. Significant changes were made to the criteria and categories of ASD. The *DSM-5* redefined ASD as a single disorder and made other changes to the diagnostic classification of ASD. These changes are discussed in detail later in this section.

Because ASD is a developmental disability, youth diagnosed with ASD require a combination and sequence of interventions and supports. These interventions are individually planned and coordinated and are of lifelong or extended duration. Such a combination of services enables individuals with disabilities to be more active, productive, and independent.

Some youth with ASD may also have diagnosable mental health disorders. Unfortunately, it is frequently assumed that behaviors associated with co-occurring mental health disorders are related to the ASD diagnosis. This assumption can leave mental health issues untreated and exacerbate symptoms.

At its November 9, 2011, meeting, the Commission on Youth recommended that the *Collection's* section on ASD be revised to include discussion of co-occurring mental health disorders and to clarify that ASD is a neurodevelopmental disorder, not a mental health disorder. Accordingly, this revised section includes additional information about ASD, as well as co-occurring mental health disorders.

#### Recent Changes from the DSM-IV-TR to the DSM-5

Prior to the May 2013 publication of the *DSM-5*, disorders classified on the autism spectrum were recognized as distinct subtypes. These subtypes included: autistic disorder, Asperger's disorder, Rett syndrome, childhood disintegrative disorder, and pervasive developmental disorder-not otherwise specified (PDD-NOS) (APA, 2000). With the publication of the *DSM-5*, all autism-related disorders were merged into the umbrella diagnosis of ASD (APA, 2013b).

The *DSM-5* reduced the *DSM-IV-TR's* three autism domains into two. Restrictive and repetitive behaviors and interests remain one domain, but social deficits and communication deficits have been combined into the second domain (Anderson, 2013). Several social/communication criteria were also merged and streamlined, and language delay was removed as a criteria. The strict requirement for onset before three years of age was changed to onset in the early developmental period (Volkmar et al., 2014). Moreover, because youth with ASD are so diverse in their symptoms and abilities, severity levels were assigned to each domain. Finally, youth with the social/communication deficits of ASD but with no issues with restricted and repetitive behaviors may receive a new diagnosis called social communication disorder (Anderson). The new criteria allow for a history of symptoms that may not be present currently, recognizing that through intervention or normal development some children with ASD no longer present some symptoms later in life.

Another change made to the *DSM-5* is that criteria for ASD and attention-deficit/hyperactivity disorder (ADHD) were modified to make it possible for youth to be diagnosed with both disorders (Anderson, 2013). This acknowledges the fact that many children are diagnosed with both ASD and ADHD, even though the *DSM-IV-TR* specifically stated that a diagnosis of ADHD could not be made in someone with ASD.

Concern has been expressed that some individuals previously given one of the *DSM-IV-TR* diagnoses may no longer meet *DSM-5* criteria for ASD, which may cause them to lose support services. However, the *DSM-5* definition includes the following statement:

Individuals with a well-established *DSM-IV* diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. (APA, 2013b)

The *DSM-5* is a manual for assessment and diagnosis of mental health disorders and does not include information for treatment of any disorder. In the future, more evidence supporting treatments of disorders with *DSM-5* classifications will be available as clinical studies utilizing *DSM-5* criteria are conducted. As a result, this *Collection* will reference studies that utilize *DSM-IV* diagnostic criteria to explain treatments.

#### **Prevalence**

According to current estimates, ASD is more prevalent in the pediatric population than Down syndrome, cerebral palsy, cystic fibrosis, muscular dystrophy, leukemia, pediatric aids, or juvenile diabetes (Autism Speaks, 2012; Talk About Curing Autism [TACA], 2015). To understand the scope of ASD in the United States, the Children's Health Act of 2000 authorized the Centers for Disease Control (CDC) to create the Autism and Developmental Disabilities Monitoring (ADDM) Network. ADDM Network. The CDC has been tracking ASD for over a decade through the Network.

Unless otherwise cited, information in the remainder of this section is taken from the CDC (Christensen, Baio, Braun et al., 2016). To estimate the prevalence of ASD, in 2012, the ADDM Network examined data obtained from 11 sites located in Arkansas, Arizona, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, South Carolina, Utah, and Wisconsin. The CDC determined that age eight was a reasonable index age to monitor peak prevalence because previous work has shown that, by this age, most children with ASD have been identified for services. These 11 communities were selected because of consistent population comprised over 8.5 percent of the U.S. population of eight-year-olds in 2012. After evaluating the data, the CDC found that overall estimated ASD prevalence in eight-year-old children for the 2012 surveillance year was 14.6 per 1,000 (1 in 68). Findings from the report include the following statistics:

- The percentage of children identified with ASD ranged widely across geographic area. For example, in the areas where the ADDM Network reviewed both health and special education records, the percentage of children who were identified with ASD ranged from a low of 1 in 81 (or 1.2 percent) in areas of South Carolina to a high of 1 in 41 (or 2.5 percent) in areas of New Jersey.
- ASD is almost 4.5 times more common among boys (1 in 42) than among girls (1 in 189).
- Caucasian children were more likely to be identified with ASD than African American or Hispanic children. African American children were more likely to be identified with ASD than Hispanic children.
- Among children identified with ASD who had IQ scores available, about a third also had intellectual disability.

• 87 percent of children later diagnosed with ASD had a documented developmental concern by age three, but less than half (43 percent) of those children received clinical developmental evaluations by age three.

Prior to this study, the ADDM Network estimated the following prevalence rates:

- 1 in 68 children in 2010
- 1 in 88 children in 2008
- 1 in 110 children in 2006
- 1 in 150 children in 2002 (data collected in 2000 and 2002) (Johns Hopkins Bloomberg School of Public Health, 2016).

It is not known whether the increase in prevalence of ASD indicates an upward trend in the actual incidence of the disorder or whether it reflects changes in identification and diagnosis. The CDC has noted that increasing awareness of ASD and improvements in the way children are identified, diagnosed, and served in their local communities have likely resulted in the increase in prevalence. In addition, ASD prevalence was significantly higher in ADDM Network sites that had access to education reporting sources, as compared to sites relying only on health sources for case identification (CDC, 2012). It is also worth noting that the surveillance areas are not representative of the United States as a whole. According to the *DSM-5*, increasing prevalence rates may also be related to expanded *DSM-IV* diagnostic criteria and associated study methodology. The *DSM-5* estimates that one percent of children in the US have ASD (APA, 2013b).

## **Causes and Risk Factors**

ASD affects youth of all racial, ethnic, and social groups. Although the causes of ASD are not yet known, it has been established that ASD is not caused by any psychological factors (National Information Center for Children and Youth with Disabilities [NICHCY], 2001). Much evidence points to a genetic basis for the disorders (Volkmar et al., 2014; Volkmar, Westphal, Gupta, & Wiesner, 2008). The number of areas affected by ASD suggests that a diverse and widely distributed set of neural systems must be affected.

The high recurrence risk for ASD in siblings, and the even higher concordance for ASD in identical twins, has provided strong support for the importance of genetic factors. Epidemiological findings reveal that ASD has heritability estimates ranging from 37 to 90 percent (APA, 2013b). As stated previously, ASD is seen more commonly in boys than girls (ratio of 4:1) and biological siblings of an affected child run a higher risk of having the disorder (APA). When evaluating siblings, when one identical twin has ASD, there is a 36 to 95 percent likelihood that the other identical twin has ASD. When one non-identical twin has ASD, there is a zero to 31 percent chance that the other twin has ASD (CDC, 2013). In non-twin siblings, when one child has ASD, there is a two to 18 percent chance that a second child will have ASD (CDC). Additionally, about 10 percent of children with ASD also have other genetic and chromosomal disorders such as Down syndrome, fragile X syndrome, or tuberous sclerosis, thus potentially linking ASD and certain genetic or chromosomal differences (CDC).

A recent study of ASD established a link between the neurotransmitter gamma-aminobutyric acid (GABA) and various symptoms of ASD. GABA inhibits brain cells from firing in response to stimuli from the outside environment (Robertson et al., 2015). The study found that, during a visual test, the brains of youth diagnosed with ASD reacted differently as compared to the brains of youth without an ASD diagnosis. This discovery offers valuable insight about ASD and the role that neurotransmitters may play.

In the recent years, there has also been a focus on searching for environmental causal factors, including immunizations, heavy metals, infectious agents, and pharmacological agents (Volkmar et al., 2008). The *DSM-5* states that a variety of nonspecific risk factors, such as advanced parental age, low birth weight, or fetal exposure to valproate (an anticonvulsant and mood stabilizer used to treat seizures and bipolar disorder and to help prevent migraine headaches), may contribute to the risk of ASD (APA, 2013b). Pre-and perinatal maternal infections and birth complications associated with ASD have also been reported with some consistency.

There has also been a focus on a possible association between childhood immunizations and ASD (Newschaffer & Curran, 2003). However, numerous studies show that vaccines do not play any role in the etiology of ASD (CDC, 2015). This is described in more detail in the Vaccines and Autism section of the *Collection*.

Studies have been conducted to identify environmental factors that may combine with or increase genetic susceptibility to ASD. Possible risk factors identified to date include:

- Deficiency in folic acid intake before conception (*American Journal of Clinical Nutrition*, Schmidt, et al. as cited by Glicksman, 2012).
- Mother's exposure to pesticides (*Environmental Health Perspective*, Shelton, et al., as cited by Glicksman, 2012).
- Mother's exposure to air pollution (*Environmental Health Perspective*, Volk, et al., as cited by Glicksman, 2012).
- Obesity in the mother (*Pediatrics*, Krakowiak, et al., as cited by Glicksman, 2012).

#### **Diagnostic Criteria**

Although the *DSM-IV* delineated categories of ASD, the *DSM-5* eliminates these categories in favor of a single diagnosis along with specifiers. A requirement for diagnosis is that the youth must meet all three behavioral criteria in the domain entitled "Social Communication & Social Interaction" and at least two of the four criteria in the domain entitled "Restrictive, Repetitive Behavior, Interests, Activities," which are outlined in Table 1. These symptoms must be present from early childhood and limit or impair everyday functioning. However, the revised criteria allow for a history of symptoms that may not be present currently, recognizing that, because of intervention or normal development, some children with ASD no longer present some symptoms later in life. Table 1 outlines the *DSM-5* diagnostic criteria for ASD.

#### Table 1

#### DSM-5 Diagnostic Criteria for ASD

#### **Social Communication & Social Interaction**

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by all three of the following, currently or by history:
  - 1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
  - 2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
  - 3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

#### Restricted, Repetitive Behavior, Interests, Activities

- B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive):
  - 1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g. simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
  - 2. Insistence on sameness, excessive adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
  - 3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g. strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
  - 4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g. apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

For A and B, current severity must also be specified. Severity is based on social communication impairments and restricted, repetitive patterns of behavior and is based on three levels defined in the DSM-5. See Table 2: Severity Levels of ASD by Domain.

#### **Other Criteria**

- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Continued on next page

# Table 1 (Continued)

#### DSM-5 Diagnostic Criteria for ASD

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Diagnosis should specify if:

- With or without intellectual impairment;
- With or without structural language impairment;
- Associated with a known medical/genetic condition or environmental' factor;
- Associated with another neurodevelopmental, mental, or behavioral disorder;
- Age at first concern;
- With or without loss of established skills; and
- Severity.

Source: APA, 2013b.

The *DSM-5* also lists three levels of severity in each of the two key domains ("social communication" and "restrictive, repetitive behavior"). Severity specifiers describe separate symptoms in each of the two domains (APA, 2013b). These severity levels are outlined in Table 2.

# **Autism Spectrum Disorder and Co-occurring Mental Health Disorders**

Recent studies have shown that mental health disorders are common and frequently multiple in children and adolescents with ASD (Ousley & Cermak, 2014; Simonoff et al., 2008). Accurate, reliable diagnosis of co-occurring mental health disorders is critical. When a youth's symptoms can be attributed to the mental health disorder, more targeted intervention is possible (Leyfer et al., 2006).

A study that examined the adjusted odds of youth with ASD being diagnosed with a co-occurring mental health disorder found that the likelihood rose significantly with each additional year of life and as ASD severity increased. This study also revealed that potentially treatable co-occurring disorders were likely to be under diagnosed. (Rosenberg, Kaufman, Law, & Law, 2011).

Table 2
Severity Levels for ASD

Severity	Social Communication	Restricted, Repetitive Behaviors
Level 3  "Requiring very substantial support"	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, if they do, makes unusual approaches to meet needs and responds to only very direct social approaches.	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors that markedly interfere with functioning in all spheres. Great distress/ difficulty changing focus or action.
Level 2  "Requiring substantial support"	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.	Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
Level 1 "Requiring support"	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

Source: APA, 2013b.

According to the *DSM-5*, approximately 70 percent of individuals with ASD may have one comorbid mental disorder, and 40 percent may have two or more comorbid disorders (APA, 2013b). ASD frequently coexists with intellectual impairment and structural language disorder (i.e., an inability to comprehend and construct sentences with proper grammar) (APA). In addition, using standardized assessments, researchers have found that one-third or more of

individuals with ASD also meet criteria for formal ADHD diagnosis, and that the most common ADHD subtypes are the predominantly inattentive type and the combined type (Ousley & Cermak, 2014). As noted previously, when criteria for both ADHD and ASD are met, both diagnoses should be given. Youth who are nonverbal or have language deficits and experience changes in sleep or eating and increases in challenging behaviors should also be evaluated for anxiety or depression.

The information in the following paragraphs is taken from Volkmar et al. (2014).

In most epidemiologically based samples of persons with ASD, approximately 50 percent exhibit severe or profound intellectual disability, 35 percent exhibit mild to moderate intellectual disability, and the remaining have IQs in the normal range. A range of behavioral difficulties can also be observed in youth with ASD, including hyperactivity, obsessive-compulsive behaviors, self-injury, aggression, stereotypies (repetitive or ritualistic movements, postures, or utterances), tics, and affective symptoms. The issue of whether these qualify as additional disorders is complex. Case reports and case series have also suggested possible associations with bipolar disorders, tics, and Tourette's syndrome. Medical conditions also commonly associated with ASD include epilepsy, sleep problems, and constipation (APA). Avoidant-restrictive food intake disorder is also a fairly frequent presenting feature of ASD and extreme and limited food preferences may also be present (APA, 2013b).

ASD also can co-exist with developmental coordination disorder, anxiety disorders, depressive disorders, and other comorbid disorders (APA, 2013b). Anxiety symptoms are one of the top treatment concerns of parents and clinicians. Parents report a high level of anxiety symptoms experienced in relation to their child's inability to accept changes in daily routines, to transition from one activity to another, to accept redirection from perseverative behaviors, or to tolerate environmental stimuli such as particular sounds. Parents also report the presence of anxiety symptoms that seem unrelated to core ASD symptoms, including specific fears, social phobia, and obsessive-compulsive behaviors.

Successful early intervention for those diagnosed with ASD includes the identification of cooccurring mental health symptoms in the toddler years (Matson, 2010). Research in this area has shown that toddlers diagnosed with ASD have more symptoms related to tantrum/conduct behavior, inattention/impulsivity, avoidance behavior, anxiety/repetitive behavior, and eating/sleep problems when compared with their same-aged peers without an ASD diagnosis who were also developing atypically. In older children diagnosed with ASD, findings have been similar.

Co-occurring mental health disorders in youth with ASD can be difficult to diagnose. This is because communication with the child or adolescent may be impaired; almost half of youth diagnosed with ASD are functionally nonverbal (Leyfer et al., 2006). Moreover, youth with ASD may also have a cognitive difficulty, which makes it difficult for them to describe their mental state. Thus, it is challenging to ascertain whether the youth's difficulties originate from the core features of their ASD or from the attributes of a co-occurring mental health disorder (Leyfer et al.). Accordingly, it may be prudent to incorporate an assessment for a co-occurring mental health disorders upon diagnosis of an ASD (Simonoff et al., 2008).

Identification and treatment of co-occurring mental health disorders in youth with ASD can result in better outcomes versus only addressing the youth's ASD symptoms (Leyfer et al., 2006). Please refer to the appropriate sections of the *Collection* for additional information on evidence-based and promising practices for the co-occurring mental health disorders discussed in this section.

# **Early Warning Signs**

Though ASD is often not diagnosed until the age of three, some children begin to show signs of developmental delay much earlier. Early identification of these signs is critical to assist in early diagnosis and intervention.

The list below contains the early warning signs published by the American Academy of Pediatrics (AAP, 2006) to aid parents and professionals with early identification and, consequently, early intervention. These are:

- Not turning when the parent says the child's name;
- Not turning to look when the parent points and says, "look at..." and not pointing themselves to show parents an interesting object or event;
- Lack of back and forth babbling;
- Smiling late; and
- Failure to make eye contact with people.

According to the AAP (2006), the following signs warrant immediate attention:

- No babbling, pointing, or other gestures by 12 months;
- No single words by 16 months;
- No two-word phrases by 24 months; and
- Regression or loss of language or social skills at any age.

It is important to understand that there is variability in the age at which children may present the features essential for this diagnosis. As noted previously, preschool children with ASD typically present with marked lack of interest in others, failures in empathy, absent or severely delayed speech and communication, marked resistance to change, restricted interests, and stereotyped movements (Volkmar et al., 2014). Common parental concerns include a child's lack of language, inconsistencies in responsiveness, or concern that the child might be deaf. In children with ASD, social and communication skills usually increase by school age; however, problems dealing with change and transitions, and various self-stimulatory behaviors (sometimes including self-injury), also may become more prominent during this time (Volkmar et al.). In adolescence, a small number of individuals with ASD make marked developmental gains; however, another subgroup may behaviorally deteriorate (e.g., tantrums, self-injury, or aggression). Earlier detection and provision of services improves long-term prognosis, thus making early diagnosis particularly important.

## **Screening and Assessment**

Multiple professional societies in the medical and child developmental fields have published specific practice parameters for the assessment and screening of ASD. There is some disagreement among these societies whether universal screening should be conducted.

The American Academy of Family Physicians has concluded that the current evidence is insufficient to assess the balance of benefits and harms of screening for ASD in children for whom no concerns of ASD have been raised by their parents or clinical provider (American Academy of Family Physicians, as cited by the U.S. Preventive Services Task Force, 2016). Moreover, the United Kingdom National Screening Committee does not recommend systematic population screening, citing concerns about the stability of ASD diagnosis at a young age, lack of data on positive predictive value, and weakness of the evidence for the efficacy of treatment (United Kingdom National Screening Committee, as cited by the U.S. Preventive Services Task Force).

The American Academy of Neurology and the Child Neurology Society recommends that routine developmental surveillance be performed on all children to identify those at risk for any type of atypical development, followed by screening specifically for ASD using a validated screening instrument (Filipek et al., as cited by the U.S. Preventive Services Task Force, 2016). The American Academy of Child and Adolescent Psychiatry (AACAP) also recommends that both the developmental assessment of young children and the psychiatric assessment of all children should routinely include questions about ASD symptomatology (Volkmar, et al., as cited by the U.S. Preventive Services Task Force), and that such practices should be clinical standards (Volkmar et al., 2014). Screening should include inquiries about the core symptoms of ASD, including social relatedness and repetitive or unusual behaviors. Screening is applicable to young children and to infants, when the diagnosis may first be considered. In some instances, screening may be relevant to older children, for example, those who are more intellectually able and whose social disability is therefore more likely to be detected later. The AACAP further recommends that if screening indicates significant ASD symptomatology, a thorough diagnostic evaluation should be performed to determine the presence of ASD (Volkmar et al.).

The American Academy of Pediatrics' Bright Futures Guidelines recommends universal screening for ASD in all children at ages 18 and 24 months in addition to developmental surveillance and monitoring (Committee on Practice and Ambulatory Medicine; Bright Futures Periodicity Schedule Workgroup, 2015). The Guidelines reflect the belief that, in order for screening to be effective, it must be applied to all children, not only those with symptoms. Screening should follow the American Academy of Pediatrics (AAP) 2007 Statement "Identification and Evaluation of Children with Autism Spectrum Disorders" (Committee on Practice and Ambulatory Medicine; Bright Futures Periodicity Schedule Workgroup). The Bright Futures Guidelines assert that that all children be screened for developmental delays and disabilities during regular well-child doctor visits at 9, 18, and 24 or 30 months. Additional screening might be needed if a child is at high risk for developmental problems because of preterm birth or low birth weight (Johnson et al., 2007).

In addition, all children should be screened specifically for ASD during regular well-child doctor visits at 18 and 24 months. Additional screening might be needed if a child is at high risk for ASD (e.g., having a sibling with ASD) or if symptoms are present (Johnson et al., 2007).

The AAP has outlined two levels of screening (Johnson et al., 2007). Level 1 screening is developmental surveillance that should be performed on all children. It involves identifying children at-risk for any type of developmental disability. If the Level 1 screening raises any cause for concern, the child should then be referred to the next level of screening (New York State Department of Health Bureau of Early Intervention, 2013). Table 3 presents the available evidence-based Level 1 screening measures.

Table 3
Level 1 Screening Instruments

Screening Tool	Age	Format (# of Items)	
Checklist for Autism in Toddlers (CHAT)	18–24+ months	Parent interview or questionnaire and interactive (parent: 9; clinician: 5)	
CHAT, Denver Modifications	18–24+ months	Parent interview or questionnaire and interactive (parent: 9; clinician: 5)	
Checklist for Autism in Toddlers-23 (CHAT-23)	16–86 months (all had mental ages of 18–24 months)	Parent interview or questionnaire and interactive (parent: 23, clinician: 5)	
Childhood Asperger Syndrome Test (CAST)	4–11 years	Questionnaire completed by parent (37)	
Modified Checklist for Autism in Toddlers (M-CHAT)	16–48 months	Questionnaire completed by parent (23)	
Pervasive Developmental Disorders Screening Test-II, Primary Care Screener (PDDST-II PCS)	18–48 months	Questionnaire completed by parent (22)	

Source: Johnson et al., 2007.

Level 2 screening of children is for those children already identified to be at risk for a developmental disorder and involves both a diagnostic evaluation and more in-depth investigation (Johnson et al, 2007). At this level, a distinction is made between ASD and other developmental disabilities and includes evaluation by ASD specialists. The goal is to determine the best means of intervention based on the child's profile of strengths and weaknesses (New York State Department of Health Bureau of Early Intervention, 2013; Siegel et al., 1998). Table 4 presents the available evidence-based Level 2 screeners/diagnostic tools for ASD.

Table 4
Level 2 Screening Instruments

Screening Tool	Age	Format (# of Items)	
Asperger Syndrome Diagnostic Scale (ASDS)	5–18 years	Questionnaire completed by parent, teacher, or clinician (50)	
Autism Behavior Checklist (ABC)	≥18 months	Behavioral checklist completed by interviewer (57)	
Autism Quotient (AQ)–Adolescent Version	11–16 years	Questionnaire completed by parent (50)	
Autism Spectrum Screening Questionnaire (ASSQ)	6–17 years	Questionnaire completed by parent (27)	
Childhood Autism Rating Scale (CARS)	>2 years	Behavioral checklist completed by trained interviewer/ observer (15)	
Gilliam Asperger's Disorder Scale (GADS)	3–22 years	Questionnaire completed by parent, teacher, or clinician (32)	
Gilliam Autism Rating Scale–2nd Edition (GARS-2)	3–22 years	Questionnaire completed by parent or teacher (42)	
Krug Asperger's Disorder Index (KADI)	6–21 years	Questionnaire completed by parent or clinician (32)	
Pervasive Developmental Disorders Screening Test-II, Developmental Clinic Screener (PDDST-II, DCS)	18–48 months	Questionnaire completed by parent (14)	
Pervasive Developmental Disorders Screening Test-II, Autism Clinic Severity Screener (PDDST-II, ACSC)	18–48 months	Questionnaire completed by parent (12)	
Screening Tool for Autism in Two- Year-Olds (STAT)	24–36 months	Interactive, requires specific training (12)	

Source: Johnson et al., 2007.

Once a child has been recognized during the screening process as being at risk for ASD, a detailed assessment should be completed to establish a diagnosis. There are several considerations important to the assessment process.

• A developmental perspective must be maintained. Since ASD is characterized by an unevenness in development that varies over the lifespan (Ozonoff, Goodlin-Jones, & Solomon, 2005), studying a child within a developmental framework provides a benchmark for understanding the severity or characteristics of delays and deviances.

- Evaluating a child with ASD should include obtaining information from multiple sources
  and contexts, as symptoms of ASD may be dependent on characteristics of the
  environment (Ozonoff, Goodlin-Jones, & Solomon). Measures of parent report, teacher
  report, and child observation across settings; cognitive and adaptive behavior
  assessments; and clinical judgments may all factor into a comprehensive assessment of
  ASD (Filipek et al., 1999).
- Assessments of ASD must be multidisciplinary whenever possible. They should incorporate findings from professionals in the fields of psychology, psychiatry, neurology, pediatrics, speech, and language (Ozonoff, Goodlin-Jones, & Solomon).

The information in the following paragraph is taken from Johnson et al. (2007). There are three major diagnostic challenges in the comprehensive assessment of a child with a suspected ASD. These are:

- 1. Determining the child's overall level of functioning;
- 2. Making the categorical diagnosis of ASD; and
- 3. Determining the extent of the search for an associated etiology.

As discussed, the evaluation should include information from multiple sources because the child's performance may vary among settings and caregivers. In order to accomplish these three goals, a comprehensive evaluation should include the following components:

- 1. Health, developmental, and behavioral histories that include at least a three-generation family pedigree and a review of systems
- 2. A comprehensive physical examination
- 3. Developmental and/or psychometric evaluations (depending on age/skill level) to determine the child's overall level of functioning and whether a discrepancy between motor-adaptive problem-solving and social communication skills is evident
- 4. The determination of the presence of a categorical *DSM*-5 diagnosis, preferably with standardized tools that operationalize the *DSM*-5 criteria
- 5. Assessment of the parents' knowledge of ASD, their coping skills, and available resources and supports
- 6. If the child has clinical features that are characteristic of a specific genetic or neurologic disorder that can be easily confirmed by a specific laboratory test, then the clinician may want to proceed with a laboratory investigation to search for a known etiology or coexisting condition guided by information obtained (Johnson et al., 2007)

The AACAP Practice Parameter, which was revised in 2014 and replaces those released in 1999, offers the following recommendations as clinical standards when assessing youth for ASD (Volkmar, et al., 2014).

- <u>Recommendation 1</u>. The developmental assessment of young children and the psychiatric assessment of all children should routinely include questions about ASD symptomatology.
- Recommendation 2. If the screening indicates significant ASD symptomatology, a thorough diagnostic evaluation should be performed to determine the presence of ASD.

• Recommendation 3. Clinicians should coordinate an appropriate multidisciplinary assessment of children with ASD.

Various instruments for the assessment of ASD have been developed and are outlined in Table 5. The AACAP Practice Parameter asserts that all of these instruments vary in their usefulness for usual clinical practice and that these instruments may need to be revised to provide evidence of validity for *DSM-5* ASD criteria. (Volkmar et al., 2014).

Table 5
Summary of Selected Assessment Instruments for Autism Spectrum Disorder

Scale	Uses	Age Range	Method of Administration
Autism Behavior Checklist (ABC)	screening	children	parent rated
Childhood Autism Rating Scale (CARS)	screening	children	clinician rated
Checklist for Autism in Toddlers (M-CHAT)	screening	toddlers	parent rated
Communication and Symbolic Behavior Scales Developmental Profile Infant-Toddler (CSBS-DP-IT) Checklist	screening	toddlers	parent rated
Autism Screening Questionnaire (ASQ)	screening	child/adult	parent rated
Autism Quotient (AQ)	screening	child/adult	self or parent rated
Childhood Autism Screening Test(CAST)	screening	4–11 years	parent rated
Asperger Syndrome Diagnostic Scale (ASDS)	screening	5–18 years	parent or teacher rated
Gilliam Asperger's Disorder Scale (GADS)	screening	3–22 years	parent or teacher rated
Asperger Syndrome Diagnostic Interview (ASDI)	screening	child/adult	interview + clinician rated
Social Responsiveness Scales (SRS)	screening	4–18 years	parent or teacher rated
Autism Diagnostic Interview–Revised (ADI)	diagnostic	child/adult	interview + clinician rated
Diagnostic Interview for Social and Communication Disorders (DISCO)	diagnostic	child/adult	interview + clinician rated
Autism Diagnostic Observation Schedule (ADOS)	diagnostic	child/adult	semi-structured interactive session

Source: Volkmar et al., 2014.

## **General Principals for Intervention**

Serving a child with ASD is determined by the child's individual needs. A combination of three principles can improve outcomes for youth with ASD, lessen challenging behavior, and provide the child with maximum independence. These are highlighted in the paragraphs that follow.

## Early Intervention

Evidence from various diagnosis and intervention research suggests that early detection of ASD is key to improving developmental outcomes (Brasic, 2015; Goin-Kochel & Myers, 2005; Dawson & Osterling, 1997). Early detection leads to early intervention, and for youth with ASD, participation in specialized intervention programs can optimize long-term outcomes (Volkmar et al., 2014). Some young children with ASD who receive early intervention have shown significant improvements in cognitive, social, and language functioning as compared to older children who undergo the same interventions (Rogers, 1998).

Evidence has shown that both younger age and more intervention hours positively affect developmental rates (Volkmar et al., 2014). Studies conducted on one specific research-proven intervention for very young children with ASD found that children aged 18 to 30 months participating in the treatment program significantly improved their IQs, social interaction, and language abilities (Pediatrics, Dawson, et al., as cited by Glicksman, 2012). Additional studies have underscored that it may be the earliness of the intervention, rather than the method itself, that leads to positive outcomes (Glicksman).

#### **Educational Intervention**

Early diagnosis and appropriate educational programs are important for youth with ASD. The appropriate goals for educational services for children with ASD are the same as those for other children. Part B of the Individuals with Disabilities Education Act (IDEA) (Public Law 94-142, Public Law 99-457, and Public Law 102-119) requires that children with a disability receive a free and appropriate education (FAPE). Children with ASD may have behavioral and communication challenges that interfere with learning. Therefore, they may benefit from an Individualized Education Program (IEP), as provided for under IDEA. The Autism Society of America recommends that IEPs are structured so that they can be carried out both at home and school (2002). Children with a disability from birth through the age three are also eligible for early intervention services under Part C of IDEA. In Virginia, parents with children between ages two and three can choose for their child to stay in Part C, early intervention services, or transition to Part B services.

Infant/toddler services under Part C of IDEA can be home-based, center-based, or a combination. The nature of the services is determined based on an assessment of the child and the family's priorities. The services provided in response to this plan may include the identification of appropriate assistive technology, intervention for sensory impairments, family counseling, parent training, health services, language services, health intervention, occupational therapy, physical therapy, case management, and transportation to services (Biasini et al., 1999).

In Virginia, the Virginia Department of Behavioral Health and Developmental Services (VDBHDS) is the lead agency that administers Part C of IDEA. Virginia's statewide early intervention system is called the Infant & Toddler Connection of Virginia. In Virginia, children from birth to age three are eligible for Part C early intervention services:

- If they have a 25-percent developmental delay in one or more areas of development;
- If they have atypical development; or
- If they are diagnosed with a physical or mental condition that has a high probability of resulting in a developmental delay (Virginia Board for People with Disabilities, 2014).

As noted previously, parents in Virginia with children between ages two and three can choose that their child to remain in Part C so that they can continue receiving early intervention services. However, once the child reaches the age of three, special education programs established by Part B of IDEA are available for the child and family (NICHCY, 2009). The services provided through IDEA to school-aged children are most often provided in home-based, center-based, or naturally occurring environments. An IEP is developed based on team evaluation and parental input. This plan describes the objectives for improving the child's skills and may include family or parent-focused activities. These services must also be provided in the least restrictive setting possible, but must provide for a continuum of placements that includes instruction in regular classes, special classes, special schools, home instruction, and instruction in hospitals and institutions. Some students with ASD who receive special education services need accommodations or modifications to their educational program in order to participate in the general curriculum and to be successful in school.

Section 504 of the Rehabilitation Act of 1973, as amended, prohibits discrimination based on a physical or mental impairment that substantially limits a major life activity (Virginia Department of Education, n.d.; Missouri Autism Guidelines Initiative [MAGI], 2012). Section 504 prohibits discrimination on the basis of handicap in any program or activity receiving federal financial assistance. A qualified child under Section 504 applies to a broader population than the definition of a child with a disability under IDEA. A qualified child under Section 504 is any person who meets one or more of the following criteria:

- Has a physical or mental impairment that substantially limits one or more major life activities
- Has a record of such an impairment
- Is regarded as having such an impairment (Virginia Department of Education)

Under Section 504, it is frequently necessary to provide accommodations or modifications to the setting or education program to allow an eligible student to access education without discrimination. In this context, the term accommodation refers to teaching supports and services that a student may require to access the curriculum (MAGI, 2012).

#### Family-centered Approach

Family involvement is a critical element of a child's educational program. A multi-disciplinary and family-focused approach, in which the service providers and the parents work in a collaborative manner to develop appropriate interventions for the child, is considered the most effective method of service delivery for children with ASD and their families (Volkmar et al., 2014; Volkmar et al., 1999). A family-centered approach employs the expertise of the family regarding the strengths and needs of the child.

For very young children, issues of diagnosis and identification of appropriate treatment programs will often be most the most important factors (Volkmar et al., 2014). For school-age children, psychopharmacologic and behavioral issues may become more prominent, whereas for adolescents, transition from middle/secondary education to postsecondary education and employment, along with planning for independence, is important (Volkmar et al., 2014). As part of this long-term engagement, parents and siblings of children with ASD will need support.

#### **About Evidence-based Practices**

There are two important resources that detail evidence-based practices and resources for children and adolescents diagnosed with ASD. Both of these initiatives were undertaken to provide information to clinicians, family members, and others because treatments for ASD are diverse and interventions with no scientific evidence were being recommended for children and adolescents with ASD (England, 2015). These two resources are discussed in the following paragraphs.

In 2008, the National Professional Development Center on Autism Spectrum Disorders (NPDC) conducted an extensive review of the autism intervention literature published between 1997 and 2007 and identified evidence-based practices for children and youth with ASD. The project utilized strict criteria relating to evidence-based practices. In 2014, the NPDC released findings from a follow-up review of studies from 1990-2011 and identified 27 practices that meet the criteria for evidence-based practice (Wong et al., 2013). The NPDC is currently developing online modules for each of the 27 identified practices.

In addition, the National Standards Project has published two reports that detail evidence-based interventions for ASD based on behavioral and educational studies. The National Autism Center first launched the project in 2005 to address the need for evidence-based practice guidelines for ASD. The National Standards Project has had the support and guidance of an expert panel composed of nationally recognized scholars, researchers, and other leaders representing diverse fields of study. Phase 1 of the National Standards Project was published in 2009. The second phase of the National Standards Project was launched in 2011 in order to provide up-to-date information on the effectiveness of a broad range of interventions for ASD (National Autism Center, 2015). The Phase 2 findings were published in 2015 and identified 14 interventions for children and adolescents that have sufficient evidence of effectiveness. Between Phase 1 and Phase 2, several interventions were moved from the "What Seems to Work" category to the "What Works" category.

Analysis of both resources conducted by the California Autism Professional Training and Information Network (CAPTAIN) has noted very little difference between the reviews conducted by these two initiatives (England, 2014). The NPDC lists interventions separately, whereas the National Standards Project discusses treatments as intervention strategies, or classes, that are clustered into packages (England). There is considerable overlap between the NPDC and the National Standards Project, with a majority of the interventions being included in both resources. The consistent theme that emerges from both projects is the importance of selecting interventions that are sufficient in their intensity and that are individualized to meet the needs of the child and the family.

### What Works - Evidence-based Practices

The treatments outlined in the following paragraphs are taken from the National Autism Center's National Standards Project (2015).

#### Behavioral Interventions

The researchers found that behavioral interventions were classified as the most effective for children and adolescents with ASD (Arick, 2015). The behavioral intervention category is comprised of interventions described as antecedent interventions and consequent interventions. Antecedent interventions involve the modification of situational events that may precede the occurrence of a target behavior. These alterations are made to increase the likelihood of success or reduce the likelihood of problems occurring. Consequent interventions involve making changes to the environment following the occurrence of a targeted behavior. Many of the consequent interventions are designed to reduce challenging behavior and teach functional alternative skills through the application of basic principles of behavior change.

# **Discrete Trial Teaching or Training (DTT)**

DTT is a behavioral intervention that focuses on the principles of operant learning to intervene with children with ASD. In DTT, children learn appropriate responses to the presence of specific words and environmental stimuli. DTT may also be called the ABC model, whereby every trial or task given to the child to perform consists of an antecedent (directive or request to the child to perform an action), behavior (response from child), and consequence (reaction from therapist). Teaching trials are repeated many times, initially in rapid succession, until the child performs a response readily, without adult-delivered prompts (Green, 1996). A pause to separate trials from each other, called the inter-trial interval, is essential. Data is kept on multiple trials, and the child moves on to additional tasks as the old ones are mastered. The child's responses are recorded and evaluated according to specific, objective definitions and criteria. Timing and pacing of teaching sessions, practice opportunities, and consequences delivery are designed precisely for each child's learning pace and style to help ensure success (Green). To maximize those successes, emerging skills are practiced and reinforced in many less-structured situations. For some highfunctioning children with ASD, certain skills can be taught entirely in relatively unstructured environments from the outset (Green). However, to ensure that these "naturalistic" practices occur frequently, the practice opportunities have to be arranged carefully and reinforcers given consistently. The overall emphasis is on teaching the child how to learn in a traditional environment and how to act on that environment in ways such that there are consistently positive outcomes for the child, their family, and others (Green; Lovaas, 1987; Lovaas & Smith, 1989).

### Cognitive Behavioral Intervention Package

Cognitive behavioral therapy has long been an evidence-based intervention for individuals diagnosed with anxiety disorders and depressive disorders (i.e., without ASD). There are manualized cognitive behavioral intervention programs that have been modified for youth and adolescents with ASD. These modifications can take different forms but usually involve making adjustments to materials (e.g., adding visual cues, role-play) or the structure of sessions. There are also cognitive behavioral intervention programs developed and individualized for specific

purposes (e.g., to address anger management). Cognitive behavioral interventions often include several commonly used strategies that include:

- An educational component describing feelings/emotions, physical responses to emotions, and prevalence of individuals with similar challenges.
- A cognitive restructuring component in which the therapist assists the individual to modify cognitive distortions such as "all-or-nothing" thinking or "catastrophizing."
- Development of scale to identify anxiety or distress. Some scales take the form of a thermometer, a ladder, or "volume control."
- Homework assignments. Individuals are expected to work on skills in the home, school, and community setting. The may be a specific assignment that requires some type of recording of behavior or observations.
- Parent sessions. Cognitive behavioral interventions often take place for 45 minutes to one hour per week for a specified number of weeks (e.g., 16 weeks). During that time, there are often "parent sessions" in which the parents and therapist meet to discuss progress and strategies to support the individual with ASD.

Some of the manualized cognitive behavioral intervention packages modified in studies reviewed in the NSP2 included The Coping Cat Program and Exploring Feelings.

# Comprehensive Behavioral Treatment for Young Children (CBTYC)

CBTYC programs involve intensive early behavioral interventions that target a range of essential skills that are associated with ASD (e.g., communication, social, and pre-academic/academic skills, etc.). These interventions are often described as applied behavior analysis (ABA), early intensive behavioral intervention (EIBI), or behavioral inclusive programs.

## Applied Behavior Analysis (ABA)

In his mental health report for children, the U.S. Surgeon General recognized applied behavior analysis (ABA) as the intervention of choice for ASD (Rosenwasser & Axelrod, 2001). ABA, also called behavioral intervention or behavioral treatment, has consistently been recognized as one of the most well-researched and effective intervention techniques for children—especially young children—with ASD (Lovaas, 1987; Dawson & Osterling, 1997; Rogers, 1998; Smith, Groen, & Wynn, 2004). According to Green (1996), ABA can be used effectively to produce comprehensive and lasting improvements in many important skill areas for most children with ASD, regardless of their age. ABA, however, is most beneficial when intervention starts before three years of age (Dawson & Osterling; Lovaas & Smith, 2003) and the child undergoes intensive behavior therapy at least 15 hours a week (Dawson & Osterling).

### Language Training (Production)

Language training (production) targets the ability of the individual with ASD to communicate verbally (i.e., functional use of spoken words). Language training (production) has recently been

moved from the "What Seems to Work" to the "What Works" category. It makes use of various strategies to elicit verbal communication from individuals with ASD and begins with appropriate assessment and identification of developmentally appropriate targets. Individualized programs often include strategies such as:

- Modeling verbalizations for the individual with ASD to imitate;
- Various prompting procedures including verbal, visual, and gestural prompts;
- Cue-Pause-Point;
- Using music as part of language training; and
- Reinforcement for display of targeted verbal response.

### Modeling

The goal of modeling is to correctly demonstrate a target behavior to encourage imitation. Children can learn a great deal from observing the behavior of parents, siblings, peers, and teachers, but they often need to be taught which behaviors should be imitated. There are two types of modeling: live and video modeling. Live modeling occurs when a person demonstrates the target behavior in the presence of the child. Video modeling occurs when the target behavior is pre-recorded. Video modeling can be a great option for children and adolescents who have an affinity for television shows and movies, or who have an interest in seeing themselves on a monitor. Some children and adolescents may enjoy assisting in the production of the video.

### Naturalistic Teaching Strategies (NTS)

NTS are a compilation of strategies that are used to teach children skills in their home, school, and community. The basic concepts include using materials in the environment and naturally occurring activities as opportunities to increase adaptive skills. These strategies are primarily child-directed.

#### Parent Training Package

The parent training package category is an addition to the interventions discussed in the Phase 1 report. Parent training package focuses on the elements of the interventions used in studies in which parents acted as therapists or received training to implement various strategies. This intervention acknowledges the critical role that parents and caregivers play in providing a therapeutic environment for their family members with ASD.

#### Peer Training Package

Difficulty interacting appropriately with peers is a commonly reported characteristic of ASD, and children with ASD often rely on adults for prompting and guidance. Peer training packages facilitate skill growth for children with ASD by training peers on how to initiate and respond during social interactions with the child with ASD. These programs have been used in school and community settings.

## Learning Experience: An Alternative Program (LEAP)

LEAP is a peer-based educational program that embraces the educational and therapeutic value of peer-mediated interventions (Kohler et al., 2005). According to Campbell et al. (2008), LEAP provides classroom instruction, parent education (as needed), and the provision of speech and occupational therapy and other services within the classroom. The range of activities varies from quiet to active, from small group to larger group, and from child- versus teacher-directed. LEAP instruction is data-driven, individualized, and focused on generalizing learning skills through saturation of learning opportunities throughout the day. Family involvement is highly encouraged in this model and entails providing classroom support and instruction. In addition, families are asked to participate in curriculum development for the teaching of core behavioral principles that increase desirable behaviors and decrease maladaptive behaviors. Peers are also actively involved in the curriculum as intervention agents. According to Campbell et al., through the use of the LEAP curriculum, children with ASD have shown decreases in ASD symptoms and long-term improvements in educational, cognitive, developmental, and social domains (Hoyson, Jamieson, & Strain, 1984; Strain & Hoyson, 2000).

# Pivotal Response Training (PRT)

PRT focuses on targeting pivotal behaviors related to motivation to engage in social communication, self-initiation, self-management, and responsiveness to multiple cues. Key to the delivery of PRT is parent involvement and implementation in the natural environment such as the home, community, and school setting. The development of PRT in part has resulted from findings from the DTT literature (Campbell et al., 2008). PRT is based on the theory that, if improvements in functioning can be achieved in the areas that are most disabling to children (i.e., pivotal areas), then effects should extend to other areas (Campbell et al.). Pivotal areas of intervention in PRT include teaching children to respond to multiple environmental cues and increasing motivation, capacity for self-management, and self-initiations. PRT has gained increasing evidence-based support in recent years (Campbell et al.; Sherer & Schreibman, 2005) and is now considered one of the more effective and proven interventions for children with ASD.

#### **Schedules**

Schedules can be used for children with ASD to increase their independence and allow them to plan for upcoming activities. A schedule simply identifies the activities that must be completed during a given time period and the order in which these activities should be completed. Children with ASD may better handle transitions when they can predict what will happen next. This can be accomplished through the use of schedules. Schedules can be used anywhere — at home, in classrooms, during doctors' visits, or on community outings. Schedules also can be used for any activity — including leisure time, social interaction, self-care, and housekeeping tasks. It is important for children and adolescents to possess prerequisite skills of picture identification (when using pictures) or reading (when using words/phrases) when considering use of schedules.

#### Scripting

Scripting occurs when a youth with ASD is provided guidance as to how to use language to initiate or respond in certain situations. These interventions involve developing an oral and/or written script about a specific skill or situation that serves as a model for the child. Scripts are

usually practiced repeatedly before the skill is used in the actual situation. Scripting has recently been established as an effective treatment (What Works).

#### Self-Management

Self-management strategies have been widely used to promote independence with tasks in which adult supervision is not needed, accepted, or expected. The process can involve teaching youth with ASD to evaluate and record their performance while completing an activity. Self-management is also used to help these individuals monitor social behaviors and disruptive behaviors. These strategies involve teaching individuals to gain access to preferred items/activities for a job well done.

## Social Skills Package

Social skills refer to a wide range of abilities, such as making eye contact appropriately, using gestures, reciprocating information, and initiating or ending an interaction. The challenges individuals with ASD face regarding social skills vary greatly. The general goal of any social skills package intervention is to provide individuals with the skills necessary to participate meaningfully in social environments.

## Story-based Intervention

Story-based interventions identify a target behavior and involve a written description of the situations under which specific behaviors are expected to occur. Most stories aim to increase perspective taking skills and are written from an "I" or "some people" perspective. The most well-known story-based intervention is Social Stories.

#### What Seems to Work

As outlined in the National Standards Project, emerging interventions (What Seems to Work) are those interventions for which one or more studies suggest they may produce favorable outcomes but additional high quality studies are needed to consistently show these interventions are effective (National Autism Center, 2015). The National Standards Project identified 18 such treatments. Based on the available evidence, these treatments should be considered by a decision-making team if treatments classified as effective (What Works) are unsuccessful in producing positive outcomes.

As outlined by the National Standards Project, research findings have shown that the following practices have emerging support (What Seems to Work) for treating ASD.

#### Augmentative and Alternative Communication Devices

Augmentative and alternative communication is any form of communication that individuals use if they are unable or unwilling to use standard forms of communication such as speech (Research Autism, 2015). Augmentative communication systems are designed to complement and/or enhance standard means of communication. Examples include, but are not restricted to, pictures, photographs, symbols, communication books, and computers or other electronic devices (National Autism Center, 2009).

#### **Developmental Relationship-based Treatment**

These treatments involve a combination of procedures that are based on developmental theory and emphasize the importance of building social relationships. These treatments may be delivered in a variety of settings (e.g., home, classroom, community). All of the studies falling into this category met the strict criteria of (a) targeting the defining symptoms of ASD, (b) having treatment manuals available, (c) providing treatment with a high degree of intensity, and (d) measuring the overall effectiveness of the program (National Autism Center, 2009). These treatment programs may be referred to by other names such as floor time, DIR (differential, individual differences, relationship-based), or relationship development intervention (RDI). Floor time has become a popular intervention among parents, but it continues to lack scientific evidence (Lindgren & Doobay, 2011). Accordingly, floor time is listed in the Unproven Practice section.

#### Exercise

These interventions involve an increase in physical exertion as a means of reducing problems behaviors or increasing appropriate behavior (National Autism Center, 2009).

## Exposure Package

These interventions require that the individual with ASD increasingly face anxiety-provoking situations. At the same time the use of maladaptive strategies used in the past is prevented (National Autism Center, 2009). Exposure treatment involves exposing youth to the non-dangerous situations that they fear, with a focus on having them learn that their anxiety will decrease over time.

## Functional Communication Training (FCT)

FCT is a behavioral method that replaces disruptive or inappropriate behavior with more appropriate and effective communication (Lindgren & Doobay, 2011). After the communicative functions of disruptive behaviors are determined through functional behavioral analysis, socially appropriate behaviors are taught as replacements for problem behaviors. FCT has been shown to significantly reduce problem behavior and to increase communication and social interaction. This intervention is very effective with young children with limited cognitive and language skills, but it can be used with individuals of all ages. When delivered through weekly training sessions with parents and their children, FCT can be a very effective and efficient intervention strategy for reducing problem behavior and increasing communication and social behavior (Lindgren & Doobay).

## Imitation-based Intervention

These interventions rely on adults imitating the actions of a child (National Autism Center, 2009).

## **Initiation Training**

These interventions involve directly teaching individuals with ASD to initiate interactions with their peers (National Autism Center, 2009).

## Language Training (Production & Understanding)

These interventions have as their primary goals to increase both speech production and understanding of communicative acts. Examples include total communication training, position object training, position self-training, and language programming strategies (National Autism Center, 2009).

## Massage Therapy

This intervention involves the provision of deep tissue stimulation (National Autism Center, 2009).

#### Multi-component Package

These interventions involve a combination of multiple treatment procedures that are derived from different fields of interest or different theoretical orientations. These treatments do not better fit one of the other treatment packages discussed in this section nor are they associated with specific treatment programs (National Autism Center, 2009).

## Music Therapy

These interventions seek to teach individual skills or goals through music. A targeted skill (e.g., counting, learning colors, taking turns, etc.) is first presented through song or rhythmic cuing and music is eventually faded (National Autism Center, 2009).

## Picture Exchange Communication System

This treatment involves the application of a specific augmentative and alternative communication system based on behavioral principles that are designed to teach functional communication to children with limited verbal and/or communication skills (National Autism Center, 2009).

## Reductive Package

These interventions rely on strategies designed to reduce problem behaviors without increasing alternative appropriate behaviors. Examples include water mist, behavior chain interruption (without attempting to increase an appropriate behavior), protective equipment, and ammonia (National Autism Center, 2009).

#### Sign Instruction

These interventions involve the direct teaching of sign language as a means of communicating with other individuals in the environment (National Autism Center, 2009).

#### Social Communication Intervention

These psychosocial interventions involve targeting some combination of social communication impairments (such as pragmatic communication skills, or the inability to successfully read social situations). These treatments may also be referred to as social pragmatic interventions (National Autism Center, 2009).

## Structured Teaching

This intervention involves a combination of procedures that rely heavily on the physical organization of setting, predictable schedules, and individualized use of teaching methods. These procedures assume that that modifications can make thinking, learning, and understanding easier for people with ASD if they are adapted to individual learning styles of autism and individual learning characteristics. All of the studies falling into this category met the strict criteria of (a) targeting the defining symptoms of ASD, (b) having treatment manuals, (c) providing treatment with a high degree of intensity, and (d) measuring the overall effectiveness of the program (e.g., conducting studies that measure subcomponents of the program). These treatment programs may also be referred to as TEACCH (Treatment and Education of Autistic and related Communication-handicapped Children) (National Autism Center, 2009).

## Technology-based Intervention

These interventions require the presentation of instructional materials using the medium of computers or related technologies. Examples include Alpha Program, Delta Messages, the Emotion Trainer Computer Program, or use of a pager, a robot, or a PDA (Personal Digital Assistant) or other hand-held mobile device. The theories behind technology-based treatments may vary but they are unique in their use of technology (National Autism Center, 2009).

## Theory of Mind Training

This training is designed to teach individuals with ASD to recognize and identify mental states in oneself or in others and to be able to take the perspective of another person in order to predict their actions (National Autism Center, 2009).

#### **Pharmacological Interventions**

Although pharmacological interventions cannot cure ASD, they may be considered for challenges such as aggression, self-injurious behavior, repetitive behaviors, sleep disturbance, anxiety, hyperactivity, inattention, destructive behavior, or other maladaptive behaviors (Myers, Johnson & the Council on Children with Disabilities, 2007). Pharmacologic interventions may increase the ability of youth with ASD to benefit from educational and other interventions and to remain in a less restrictive environment through the management of severe and challenging behaviors (Volkmar et al., 2014). After treatable medical causes and environmental factors have been ruled out, medication may be considered when behavioral symptoms cause significant impairment in functioning. It is important to note that these drugs do not alter or improve core ASD characteristics

Antipsychotics (e.g., risperidone), selective serotonin reuptake inhibitors (SSRIs), and stimulants have been tested in different clinical studies with some proven benefits (Lindgren & Doobay, 2011). Antipsychotics such as risperidone and aripiprazole have been approved by the Food and Drug Administration for the treatment of irritability, consisting primarily of physical aggression and severe tantrum behavior, associated with ASD (Volkmar et al., 2014). As noted in the updated AACAP Practice Parameter, the combination of medication with parent training is moderately more efficacious than medication alone for decreasing serious behavioral disturbances, and modestly more efficacious for adaptive functioning (Volkmar et al.). However, evidence also supports significant adverse effects of these medications (McPheeters et al., 2011). More rigorous, controlled studies are called for to establish the evidence-base of intervention efficacy (Myers, Johnson, & the Council on Children with Disabilities, 2007). Youth with ASD may be nonverbal, so treatment response is often judged by caregiver report and observation of specific behaviors (Volkmar et al.).

A recent study revealed that almost one in ten youth treated with antipsychotic medications were diagnosed with ASD and/or intellectual disability, and one in six youth with ASD received antipsychotics (Part et al., 2016). The study noted that both proportions increased in later years. This study also reiterated that the side effects of antipsychotics could be quite problematic, especially in children and adolescents. The researchers stated that clinicians should carefully assess the benefits and the risks prior to starting youth with ASD or intellectual disability on an antipsychotic, and that they should attempt to maximize non-pharmacologic interventions for comorbid disorders. Based on the study results and the known adverse effects of antipsychotics, the authors concluded that clinicians should consider using psychosocial interventions that are proven to be effective for behavioral dysregulation such as irritability and aggression before prescribing antipsychotics to adolescents with ASD or intellectual disability. The authors further stressed that, because outcomes of antipsychotic use in youth with ASD and/or intellectual disability require further study, it is imperative to regularly monitor both their efficacy and tolerability (Part et al.).

## **Unproven Practices**

The following are complementary and alternative intervention approaches for which there is conflicting data on their effectiveness (National Autism Center, 2015).

- Animal-assisted therapy
- Auditory Integration Training
- Concept mapping
- DIR/Floor time
- Gluten-free and/or casein-free diet
- Facilitated communication
- Movement-based intervention
- Sensory integration
- Shock therapy
- Social-behavioral learning strategy (e.g., SODA)
- Social cognition/social thinking intervention program
- Holding therapy (Ennis-Cole, Durodoye, & Harris, 2013)

Table 6
Summary of Interventions for ASD

What Works	
Behavioral interventions	Includes antecedent interventions and consequent interventions.
Discrete trial teaching or training (DTT)	A type of behavioral intervention that uses operant learning techniques to change behavior. Also known as the ABC model (action request, behavior, consequence).
Cognitive behavioral intervention package	CBT modified for ASD youth
Comprehensive behavioral treatment for young children (CBTYC)	Also known as applied behavior analysis (ABA), early intensive behavioral intervention (EIBI), and behavioral inclusive programs.
Language training (production)	Targets the ability to communicate verbally
Modeling	Involves demonstrating a target behavior to encourage imitation
Naturalistic teaching strategies (NTS)	Child-directed strategies that use naturally occurring activities to increase adaptive skills
Parent training package	Involves training parents to act as therapists
Peer training package	Involves training peers on how to behavior during social interactions with a youth with ASD
Learning experience: An alternative program (LEAP)	A type of peer training program for peers, teachers, parents, and others
Pivotal response training (PRI)	Involves targeting pivotal behaviors related to motivation to engage in social communication, self-initiation, self-management, and responsiveness to multiple cues
Schedules	Used to increase independence in youth with ASD
Scripting	Providing scripted language to be used as a model in specific situations
Self-management	Strategies that involve teaching youth to track performance while completing an activity
Social skills package	Aims to provide youth with the skills (such as making eye contact appropriately) necessary to participate in social environments
Story-based intervention	Use stories to increase perspective taking skills

# Table 6 (continued)

# Summary of Interventions for ASD

What Seems to Work	
Augmentative and alternative communication devices	Communication systems designed to complement speech (pictures, symbols, etc.)
Developmental relationship- based treatment	Programs that emphasize the importance of building social relationships by using the principals of developmental theory
Exercise	Uses physical exertion to regulate behavior
Exposure package	Requires youth to face anxiety-provoking situations
Functional communication training (fct)	Behavioral method that replaces disruptive or inappropriate behavior with more appropriate and effective communication
Imitation-based intervention	Relies on adults imitating the actions of a child
Initiation training	Involves directly teaching individuals with ASD to initiate interactions with their peers
Language training (production and understanding)	Aims to increase both speech production and understanding of communicative acts.
Massage therapy	Involves the provision of deep tissue stimulation
Multi-component package	Involves a combination of multiple treatment procedures that are derived from different fields of interest or different theoretical orientations.
Music therapy	Aims to teach individual skills or goals through music
Picture exchange communication system	Involves the application of a specific augmentative and alternative communication system for youth with limited communication skills
Reductive package	Relies on strategies designed to reduce problem behaviors without increasing alternative appropriate behaviors
Sign instruction	Teaches sign language as a means of communicating
Social communication intervention	Targets some combination of social communication impairments
Structured teaching	Relies heavily on the physical organization of setting, predictable schedules, and individualized use of teaching methods
Technology-based intervention	Presents instructional materials using the medium of computers or related technologies
Theory of mind training	Aims to teach youth to recognize and identify the mental states of others

#### Table 6 (continued)

#### Summary of Interventions for ASD

#### **Not Adequately Tested**

- Animal-assisted therapy (e.g., hippotherapy: the use of horseback riding as a therapeutic or rehabilitative treatment)
- Auditory integration training
- Concept mapping
- DIR/Floor time
- Gluten-free and/or casein-free diet
- Facilitated communication
- Movement-based intervention
- Sensory integration
- Shock therapy
- Social-behavioral learning strategy (e.g., SODA)
- Social cognition/social thinking Intervention program
- Holding therapy

#### **Vaccines and Autism**

Concern has been expressed during the past decade about vaccines and their role in the development of ASD. It was theorized that a link might exist between ASD and the use of thimerosal, a mercury-based preservative once used in the measles-mumps-rubella (MMR) vaccine (National Institute of Mental Health [NIMH], 2007). Although mercury is no longer used in childhood vaccines in the United States, some parents expressed concerns about vaccinations (NIMH). In May 2004, the Institute of Medicine (IOM) released a report that stated that thimerosal had no causal relationship with the development of ASD (NIMH).

In 2008, in response to persisting public concerns, the CDC commenced a study on thimerosal and ASD using data obtained from managed care organizations in the U.S. to determine whether exposure to thimerosal in infancy was related to ASD. The study's goal was to provide the best available scientific information about whether there is a causal association between exposure to thimerosal and the development of ASD. Study findings showed that prenatal and infant exposure to vaccines containing thimerosal did not increase risk for ASD (Price et al., 2010). Researchers also noted that these results applied to both boys and girls. The outcome noted by the CDC was that thimerosal-containing immunizations did not increase the risk of any of the ASD outcomes (Price et al.). The recommended vaccination course for all children continues to be two doses of MMR vaccine (CDC, 2007).

Under the National Childhood Vaccine Injury Act of 1986, Congress established the National Vaccine Injury Compensation Program (VICP) to provide compensation to people injured by vaccines (Institute of Medicine [IOM], 2011). The Health Resources and Services Administration (HRSA) asked the IOM to review a list of adverse events associated with eight of the 12 vaccines covered by VICP and to evaluate the scientific evidence about the event. The vaccines were those recommended by the CDC for routine administration in children and included the MMR vaccine (IOM). An analysis of more than 1,000 research articles concluded

that few health problems were caused by, or clearly associated with, these vaccines (IOM). The report also asserted there was no link between immunizations and serious conditions that have raised concerns, including Type 1 diabetes and ASD (IOM). The data were inadequate to reach conclusions about other suggested adverse effects.

A 2013 CDC study added to the research asserting vaccines do not cause ASD. The study examined the number of antigens (substances in vaccines that cause the body's immune system to produce disease-fighting antibodies) from vaccines during the first two years of life. The results showed that the total amount of antigen from vaccines received was the same between children with ASD and those that did not have ASD (DeStefano, Price, & Weintraub, 2013).

A study published in 2015 also found that receipt of the MMR vaccine was not associated with increased risk of ASD, regardless of whether older siblings had ASD (Marshall et al., 2015). Study participants included children continuously enrolled in a health plan from birth to at least five years of age from 2001 to 2012 who also had an older sibling continuously enrolled for at least six months between 1997 and 2012. These findings indicate no harmful association between MMR vaccine receipt and ASD, even among children already at higher risk for ASD (Marshall et al.).

## **Activities in Virginia**

In recent years, Virginia has responded to rising concerns about the Commonwealth's ability to provide high quality services to children diagnosed with ASD. In 2006, the Virginia Department of Behavioral Health and Developmental Services (VDBHDS), formerly the Department of Mental Health, Mental Retardation and Substance Abuse Services, convened a workgroup to assess how to best provide a coordinated response to educating and treating individuals with ASD. In 2007 the workgroup developed recommendations to address services and supports, including one to establish a central agency for ASD.

In 2007, the Joint Commission on Health Care (JCHC) convened the Workgroup Regarding the Commonwealth's Ability to Serve Children and Adults with Autistic Spectrum Disorder (ASD). The workgroup's objective was to recommend a primary agency for developing, coordinating, and overseeing autism services. This agency, as envisioned, would serve as the primary entity to oversee the provision of services for individuals diagnosed with ASD. The JCHC recommended having the Secretary of Health and Human Resources develop a plan to identify the state agency to be responsible for serving individuals with ASD and whether that agency should serve individuals with only ASD or with all developmental disabilities.

In 2008 the Virginia General Assembly passed House Joint Resolution 105, which directed the Joint Legislative Audit Review Commission (JLARC) to examine services available to Virginians with ASD. JLARC compared Virginia services to those provided in other states, assessed the availability of ASD training for public safety personnel, and identified best practices and ways to improve delivery of services to Virginians. Findings from this comprehensive review can be accessed on the JLARC website (Virginia Joint Legislative Audit and Review Commission, 2009).

One recommendation from the JLARC study was:

The Department of Behavioral Health and Developmental Services should create a detailed action plan reflecting the input of relevant stakeholders and the evaluation of options conducted by other State agencies, which specifies how the department will address the issues contained in this report and build a more effective system of care for Virginians with developmental disabilities, including autism spectrum disorders.

The status of the resulting plan can be accessed on the Department's website (Virginia Department of Behavioral Health and Developmental Services, 2013).

In 2011, legislation was passed requiring health insurance plans in businesses employing at least 50 people to offer coverage for ASD for 2 to 6 year olds (House Bill 2467/Senate Bill 1062). The Governor amended this legislation to license board certified behavior analysts (BCBAs). The legislation, however, did not authorize the Virginia Board of Medicine to promulgate regulations to govern the licensure. In 2012, legislation (House Bill 1106) was passed to require the Board of Medicine to license behavior and assistant behavior analysts. The bill also required the Board to convene a workgroup relating to the licensure and practice of applied behavior analysis and contained an emergency clause that requires the Board to promulgate emergency regulations within 280 days of enactment.

Additional legislation was passed by the 2012 General Assembly with the goal of improving delivery of school-based services to youth with ASD (House Bill 325). This legislation required school divisions to ensure that aides assigned to work with a teacher who has primary oversight of students with ASD receive training in student behavior management within 60 days of assignment to such responsibility. School boards may also provide such training to other employees, including transportation employees. The Virginia Board of Education must provide training standards that school divisions may use to fulfill the training requirement. An enactment clause was added requiring the Virginia Board of Education, in consultation with Virginia Commonwealth University, to develop online training that school divisions may use to fulfill the requirements of this legislation. Such training must be made available to local school divisions free of charge.

In 2014, the General Assembly enacted legislation (House Bill 926) that established the Advisory Board on Behavior Analysis to advise the Virginia Board of Medicine on issues related to licensure of behavior analysts and assistant behavior analysts. In addition, the legislation provided for several exceptions to the licensure requirements. In 2015, the General Assembly enacted legislation (House Bill 1940) requiring health insurers, health care subscription plans, and health maintenance organizations to provide coverage for the diagnosis and treatment of ASD in individuals from ages two years through 10 years. The legislation does not apply to policies, contracts, or plans issued in the individual market or the small group market, which effective January 1, 2016, includes employers with no more than 100 employees.

In 2011, the Virginia General Assembly created the Virginia Autism Advisory Council (Senate Bill 1269). The Virginia Autism Council is the legislative body charged with promoting coordination of services and resources among agencies involved in the delivery of services to Virginians with autism spectrum disorders (ASDs) and increasing public awareness of such

services and resources. The Council is to submit an annual report with progress updates and recommendations to the Governor and the General Assembly. The Council had a sunset provision, meaning that the statutory language creating the Council would expire July 1, 2016; however, legislation was enacted during the 2016 General Assembly Session (Senate Bill 225) that extended the sunset provision for the Council to July 1, 2018. The Council adopted a work plan in 2014 that tasked the Council with formulating potential strategies for lowering Virginia's current Medicaid waiver waiting lists and evaluating the adequacy of the Commonwealth's current employment support programs and efforts for students with ASD. The Council adopted a recommendation to continue assessing the issue of uniform application of dyslexic and ASD support across the Commonwealth. The Council invited parents of children with ASD and dyslexia from various regions in the Commonwealth to testify before the Council regarding their satisfaction and experiences with the services being provided in their area. The Council included in its work plan the issue of proper diagnosis (Virginia Autism Advisory Council, 2015).

In Virginia, individuals with ASD may be eligible to receive services from Virginia's Home and Community-based Medicaid Waivers program. Medicaid waivers provide funding for services that allow individuals with developmental disabilities, including those with ASD, to live in their homes/communities rather than reside and receive services in an institution.

In 2013, Virginia's Medicaid agency, the Department of Medical Assistance Services, and Virginia's Department of Behavioral Health and Developmental Services (Virginia's agency with operational authority for Virginia's waivers) undertook a study of three of Virginia's six existing Medicaid waivers (Virginia Department of Medical Assistance Services [VDMAS] & Virginia Department of Behavioral Health and Developmental Services [VDBHDS], 2015). The study reviewed Virginia's Intellectual Disability (ID) Waiver, the Individual and Family Developmental Disability (DD) Supports Waiver, and the Day Support (DS) Waiver. Currently, Virginia's ID, DD, and DS Waivers distinguish eligibility separately between those with intellectual disability and those with a developmental disability. However, developmental disability is an umbrella term that includes individuals with intellectual disability. Accordingly, these three waivers are in the process of being revised to better serve individuals with a diagnosis of intellectual disability or a developmental disability. Under the current system, an individual with a diagnosis of ASD, but no specific diagnosis noting an intellectual disability, would only be eligible to receive services under the DD Waiver. In the new plan, the three waivers will be open to all eligible individuals, creating a unified system for individuals to access waiver services (VDMAS & VDBHDS).

The following are the waivers proposed to replace the existing ID/DD waivers:

- The current Day Support Waiver will become the "Building Independence" Waiver and
  provide supports for adults able to live independently in the community, with other
  support and or housing subsidies as needed.
- The current Developmental Disabilities Waiver will become the "Family and Individual Supports" Waiver and provide supports for individuals living with their families, friends, or in their own homes, including supports for those with some medical or behavioral needs. It will be available to children and adults.

• The current Intellectual Disability Waiver will become the "Community Living" Waiver and provide up to and including 24/7 services and supports for individuals with exceptional medical and/or behavioral support needs through licensed services. This waiver will include residential supports and a full array of medical, behavioral, and nonmedical supports. It will be available to adults and some children (e.g., those who require out-of-home residential supports) (VDMAS & VDBHDS, 2015).

The new waivers are to be implemented in two phases. The redesigned waivers include new services. They will have a nondiagnosis specific eligibility. Eligibility will be assessed based on a newly revised instrument (the VIDES) and level of need will be determined through use of the nationally validated Supports Intensity Scale (SIS). SIS scores will be used to determine provider reimbursement according to tiers for certain services. In addition, the Commonwealth will transition to a single statewide waiting list based on priority of need. Currently the DD Waiver waiting list is chronological and the ID waiver waiting list is based on local prioritization.

Another Virginia Medicaid Wavier also serves individuals with ASD. The Elderly or Disabled with Consumer Direction (EDCD) Waiver provides services that help individuals live in their own home or community instead of a nursing home. It is available to individuals 65 years of age and older, and to individuals of any age who have a disability. Individuals who depend on another person for supports and have medical or nursing needs may be eligible for the EDCD Waiver (Virginia Department for the Aging and Rehabilitative Services, 2008).

#### **Cultural Considerations**

Cultural differences for youth diagnosed with ASD exist in norms for social interaction, nonverbal communication, and relationships. Cultural and socioeconomic factors may also have an impact upon the individual's age at diagnosis (APA, 2013b). As discussed in the preceding section on prevalence, the most recent data on ASD prevalence was gathered in 2012 through the active surveillance system, Autism and Developmental Disabilities Monitoring Network (ADMM). The surveillance found that Caucasian children were more likely to be identified with ASD than African American or Hispanic children, and that African American children were more likely to be identified with ASD than Hispanic children. In order to receive early intervention, an accurate diagnosis is essential, which means the signs of developmental delay must be recognized and explored as soon as possible. Minority families may view developmental delays as temporary and even normal (Ennis-Cole, Durodoye, & Harris, 2013). As a result, they may not identify subtle but meaningful warning signs for ASD (lack of pointing, lack of imitation, lack of eye contact, and lack of socially appropriated behavior) (Ennis-Cole, Durodoye, & Harris).

Traditional cultural perspectives may also influence treatment recommendations. Parent with information about interventions and practices that have strong research support are in a better position to select interventions that may be helpful for their children.

#### **Overview for Families**

The information discussed in this section is derived from the American Academy of Child and Adolescent Psychiatry Facts for Families Guide to Autism (2013).

Most infants and young children are very social creatures who want contact with others and need that contact to thrive and grow. They smile, cuddle, laugh, and respond eagerly to games like peek-a-boo or hide-and-seek. Occasionally, however, a child does not interact in this expected manner. Instead, the child seems to exist in his or her own world, a place characterized by repetitive routines, odd and peculiar behaviors, problems in communication, and a total lack of social awareness or interest in others. These are characteristics of a developmental disorder called Autism Spectrum Disorder (ASD).

ASD is usually identified by the time a child is 30 months old. It is often discovered when parents become concerned that their child may be deaf, is not yet talking, resists cuddling, and/or avoids interaction with others. Some of the early signs and symptoms that suggest a young child may need further evaluation for ASD include:

- No smiling by six months of age
- No back-and-forth sharing of sounds, smiles, or facial expressions by nine months
- No babbling, pointing, reaching, or waving by 12 months
- No single words by 16 months
- No two word phrases by 24 months
- Regression in development
- Any loss of speech, babbling, or social skills

A preschool age child with ASD is generally withdrawn, aloof, and fails to respond to other people. Many of these children will not even make eye contact. They may also engage in odd or ritualistic behaviors like rocking, hand flapping, or an obsessive need to maintain order. Many children with ASD do not speak at all. Those who do may speak in rhyme, have echolalia (repeating another person's words like an echo), refer to themselves as a "he" or "she," or use peculiar language.

The severity of ASD varies widely, from mild to severe. Some children are very bright and do well in school, although they have problems with school adjustment. They may be able to live independently when they grow up. Other children have significantly more challenges. Intellectual disability may or may not be a concurrent diagnosis.

The cause of ASD remains unknown. Children with ASD need a comprehensive evaluation and specialized behavioral and educational programs. Typically, a multi-disciplinary team diagnoses ASD. Such a team may include a developmental pediatrician, a neurologist, a neuropsychologist, and perhaps at times a psychiatrist. These providers can help families design and implement an appropriate treatment plan, which usually includes educational components.

Although there is no cure for ASD, appropriate specialized treatment provided early in life can have a positive impact on children's development and help them to achieve the best possible outcomes.

#### Conclusion

Each child and adolescent with ASD is unique, with differing strengths and needs. New evidence and information on ASD is being published almost daily. Early identification and intervention

are key elements influencing long term outcomes for children and youth with an ASD diagnosis. Multi-disciplinary evaluations and child- and family-centered service planning are critical to assisting the child in improving communication and social skills, achieving educational and employment goals, and becoming as independent as possible.

## **Resources and Organizations**

## **American Academy of Pediatrics**

http://www.aap.org

## **Autism Focused Intervention Resources and Modules (AFIRM)**

An extension of the National Professional Development Center (NPDC)

http://afirm.fpg.unc.edu/selecting-ebp

## **Asperger Syndrome Education Network (ASPEN)**

http://www.aspennj.org

## **Association of University Centers on Disabilities**

http://www.aucd.org

#### **Autism and PDD Support Network**

http://www.autism-pdd.net

## **Autism Research Institute (ARI)**

4182 Adams Avenue – San Diego, CA 92116

https://www.autism.com/index.asp

## **Autism Society of America**

7910 Woodmont Avenue, Suite 300 – Bethesda, MD 20814-3067 http://www.autism-society.org/

#### **Autism Speaks**

2 Park Avenue, 11th Floor – New York, NY 10016 http://www.autismspeaks.org

#### **Autism Spectrum Connection**

http://www.aspergersyndrome.org/

#### **Centers for Disease Control and Prevention**

Autism Spectrum Disorder (ASD)

http://www.cdc.gov/ncbddd/autism/index.html

#### **Center for Parent Information and Resources**

http://www.parentcenterhub.org/

## **Individuals with Disabilities Education Act (IDEA)**

https://sites.ed.gov/idea/

## **Interagency Autism Coordinating Committee**

https://iacc.hhs.gov/

#### **National Autism Center**

http://www.nationalautismcenter.org

#### **National Alliance for Autism Research**

99 Wall Street, Research Park – Princeton, NJ 08540

## **National Institute of Child Health and Human Development**

https://www.nichd.nih.gov/Pages/index.aspx

#### **National Institute of Mental Health (NIMH)**

6001 Executive Blvd., Rm. 8184, MSC 9663 – Bethesda, MD 20892-9663 https://www.nimh.nih.gov/index.shtml

## **National Institute on Deafness and Other Communication Disorders**

31 Center Drive, MSC 2320 – Bethesda, MD 20892-2320 http://www.nided.nih.gov

#### **National Network for Immunization Information (NNii)**

https://www.immunizationinfo.net/

## **National Professional Development Center (NPDC)**

http://autismpdc.fpg.unc.edu/

## U.S. Autism & Asperger Association

http://www.usautism.org

## **U.S. Department of Education**

U.S. Office of Special Education and Rehabilitative Services 400 Maryland Ave., S.W. – Washington, DC 20202-7100

## **U.S. Department of Health and Human Services**

The Interagency Autism Coordinating Committee (IACC) https://iacc.hhs.gov/

## **Wrights Law**

http://www.wrightslaw.com/

## Virginia Resources and Organizations

## Autism Outreach, Inc.

http://autismoutreach.org/

## **Autism Society of America**

Central Virginia Chapter
P.O. Box 29364 – Richmond, VA 23242-0364
http://ascv.org

#### **Commonwealth Autism**

4108 E. Parham Road – Henrico, VA 23228 http://www.autismva.org/

## **Virginia Department of Behavioral Health and Developmental Services (VDBHDS)**

Infant & Toddler Connection of Virginia

1220 Bank Street, 9th Floor – P.O. Box 1797 – Richmond, VA 23219-1797 http://www.infantva.org/

## **Parent Educational Advocacy Training Center (PEATC)**

6320 Augusta Drive, Suite 1200 – Springfield, VA 22150 http://www.peatc.org/

## Partnership for People with Disabilities

https://partnership.vcu.edu/

## The Radford University Autism Center

Department of Communication Sciences & Disorders

P.O. Box 6961 – Radford, VA 24142

http://www.radford.edu/content/wchs/home/cosd.html/autism.html

## Virginia Autism Advisory Council

http://www.autismtrainingva.org/

## Virginia Autism Project

http://www.virginiaautismproject.com/

## Virginia Autism Resource Center

Richmond Office: 4100 Price Club Boulevard – Midlothian, VA 23112

Winchester Office: P.O. Box 2500 - Winchester, VA 22604

http://www.varc.org/

## Virginia Board for People with Disabilities

https://www.vaboard.org/

## **Virginia Commonwealth University Autism Center for Excellence (VCU-ACE)**

1314 West Main Street – Richmond, VA 23284

http://www.vcuautismcenter.org/projects/diagnosis.cfm

## Virginia Department for Aging and Rehabilitative Services

8004 Franklin Farms Drive – Henrico, VA 23229-5019

https://vadars.org/

## Virginia Department of Behavioral Health and Developmental Services

Office of Developmental Services

P.O. Box 1797 - Richmond, VA 23219

http://www.dbhds.virginia.gov/developmental-services

## Virginia Department of Education

Office of Special Education and Student Services

P.O. Box 2120 – Richmond, VA 23218-2120

http://www.doe.virginia.gov/about/spec ed and stu svs/index.shtml

Autism Spectrum Disorders

http://www.doe.virginia.gov/special\_ed/disabilities/autism/index.shtml

Autism Spectrum Disorders and the Transition to Adulthood

http://www.doe.virginia.gov/special\_ed/disabilities/autism/technical\_asst\_documents/autism transition.pdf

Guidelines for Educating Students with Autism Spectrum Disorders

http://www.doe.virginia.gov/special\_ed/disabilities/autism/technical\_asst\_documents/autism guidelines.pdf

Models of Best Practice in the Education of Students with Autism Spectrum Disorders

http://www.doe.virginia.gov/special\_ed/disabilities/autism/technical\_asst\_documents/autism \_models\_of\_best\_practice.pdf

#### Virginia Department of Health

Child & Adolescent Health, Division of Child & Adolescent Health 109 Governor Street, 8<sup>th</sup> Floor – Richmond, VA 23219 http://www.vdh.virginia.gov

## Virginia Department of Medical Assistance Service

600 East Broad Street – Richmond, VA 23219 http://www.dmas.virginia.gov/

#### **Virginia Institute of Autism**

1414 Westwood Road – Charlottesville, VA 22903-5149 http://www.viaschool.org

#### **Virginia Tech Autism Clinic**

3110 Prices Fork Road – Blacksburg, VA 24061 http://www.psyc.vt.edu/outreach/autism

## Virginia's Training/Technical Assistance Centers (TTAC)

http://ttaconline.org/

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# ATTENTION-DEFICIT/HYPERACTIVITY DISORDER

Introduction

Recent Changes from the DSM-IV to the DSM-5
Characteristics of ADHD
Prevalence
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#### Introduction

**Overview for Families** 

Attention deficit hyperactivity disorder (ADHD) is an increasingly prevalent childhood disorder (Centers for Disease Control [CDC], 2013). The Mayo Clinic defines ADHD as a combination of problems to include sustaining attention, hyperactivity, and impulsive behavior. ADHD can also influence self-esteem, relationships, and school performance (2014).

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) classifies ADHD as a neurodevelopmental disorder with its onset occurring during the developmental period (American Psychiatric Association [APA], 2013).

ADHD is classified as a chronic disorder. Children with ADHD typically do not outgrow the disorder, although they may experience some reduction in symptoms of hyperactivity. Studies report that as many as 80 percent of children diagnosed with ADHD will continue to show symptoms into adolescence and as many as 65 percent will remain symptomatic into adulthood (American Academy of Child & Adolescent Psychiatry [AACAP], 2007).

Numerous studies have documented youth with ADHD having serious chronic impairment in their social aptitude, emotional well-being, family relationships, and academic functioning (Anastopoulos et al., 1992; Anastopoulos et al., 1993; Barkley et al. 1992; Barkley et. al., 2001; Cunningham, Benness, & Siegel, 1988; Whalen et al., 2002). Youth with ADHD are more likely than their non-ADHD peers to engage in risky behaviors, including tobacco and alcohol use (Sibley et al., 2011). Compared to their peers, these youth have more difficulty in school, are more likely to be retained a grade, and are less likely to graduate from high school. Moreover,

these youth frequently experience peer rejection, academic struggles, and social difficulties, all of which may have long-term effects (Sibley et al.).

## Recent Changes from the DSM-IV to the DSM-5

In 2013, the American Psychiatric Association released the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. The *DSM-5* characterizes ADHD as a pattern of behavior, in multiple settings, that can result in issues of performance. It also reclassifies ADHD as a neurodevelopmental disorder. While the behavioral pattern symptoms for ADHD remain the same in the *DSM-5*, it now provides specific examples of what that behavior might look like.

Changes in the *DSM-5* that could affect diagnosis criteria are as follows:

• The cutoff age for the onset of symptoms was raised from age seven to age 12 to reflect the fact that inattentive and/or hyperactive-impulsive symptoms can begin later in childhood.

This later onset date also reduces unreliable adult recall of childhood symptoms and the difficulty of establishing "precise childhood onset retrospectively."

- ADHD and autism spectrum disorder (ASD) can be simultaneously diagnosed so that a co-occurring diagnosis of ASD no longer excludes a diagnosis of ADHD.
- Only five instead of six criteria are now required for diagnosis in individuals aged 17 years or older.
- The *DSM-5* provides criterion that allows children with ADHD to continue receiving care into adulthood (APA, 2013; French, 2015).
- The subtype, ADHD Not Otherwise Specified (NOS), has been replaced with the following two categories:

Other Specified ADHD encompasses symptoms similar to ADHD that cause significant distress or impairment, but these symptoms do not meet diagnostic criteria for ADHD (APA, 2013). The clinician here will specify why the diagnostic criteria are not met, such as "Other Specified Attention-Deficit/Hyperactivity Disorder with insufficient attention symptoms" (APA).

**Unspecified ADHD** encompasses symptoms similar to ADHD that cause significant distress or impairment, but these symptoms do not meet the diagnostic criteria (APA, 2013). However, the clinician does not specify why the diagnostic criteria are not met. This is often because the clinician does not have sufficient information to make a specific diagnosis (e.g., the child is being seen in the emergency room) (APA; French, 2015).

The *DSM-5* is a manual for assessment and diagnosis of mental health disorders and does not include information for treatment of any disorder. In the future, more evidence supporting

treatments of disorders with *DSM-5* classifications will be available as clinical studies utilizing *DSM-5* criteria are conducted

#### Characteristics of ADHD

ADHD is characterized by inattention and hyperactivity/impulsivity. The child must exhibit at least six symptoms for more than six months in one of the two categories to be diagnosed with ADHD (APA, 2013). Several of the symptoms must have been present before the age of 12, must be present in two or more settings, must interfere with quality of life, and must not occur exclusively during the course of schizophrenia or another psychotic disorder (APA).

ADHD is also broken down into three subcategories (APA 2013).

- **Predominantly Hyperactive-Impulsive Type:** if hyperactivity-impulsivity criteria are met but inattention is not for the past six months.
- **Predominantly Inattentive Type:** if the inattention criteria are met but the hyperactivity-impulsivity is not for the past six months. (Also referred to as attention-deficit disorder (ADD), although the preferred term is ADHD, Predominately Inattentive Type.)
- **Combined Presentation:** if symptoms of both inattention and hyperactivity-impulsivity criteria are met for the last six months or more.

The symptoms of inattention according by the APA (2013) are as follows:

#### The child often:

- Fails to give close attention to details or makes careless mistakes in schoolwork, work, or other activities
- Has difficulty sustaining attention in tasks or play activities
- Does not seem to listen when spoken to directly
- Does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behavior or failure of comprehension)
- Has difficulty organizing tasks and activities
- Avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (such as schoolwork or homework)
- Loses things necessary for tasks or activities at school or at home (e.g. toys, pencils, books, assignments)
- Is easily distracted by extraneous stimuli
- Is forgetful in daily activities

The symptoms of hyperactivity and impulsivity, according to the APA (2013), are as follows:

#### The child often:

- Fidgets with or taps hands or feet or squirms in seat
- Leaves seat in the classroom or in other situations in which remaining seated is expected
- Runs or climbs in situations in which it is inappropriate (in adolescents or adults, may be limited to subjective feelings of restlessness)
- Is unable to play or engage in leisure activities quietly
- Talks excessively
- Is "on the go" or acts as if "driven by a motor"
- Has difficulty waiting for his or her turn in games or in group situations
- Blurts out answers to questions before they have been completed
- Interrupts or intrudes on others (e.g., butts into other children's games)

ADHD can be in "partial remission" if fewer than the full diagnostic criteria were present for the previous six months or more. The symptoms must still impair social or academic functioning (APA, 2013). Levels of severity may be applied to a diagnosis.

- **Mild** Few, if any, symptoms in excess of those required to make the diagnosis are present, and symptoms only impair social or academic functioning minimally.
- **Moderate** Symptoms, or functional impairment between "mild" and "severe" are present.
- **Severe** Many symptoms in excess of those required for diagnosis, or several symptoms that are particularly severe, are present; or the symptoms cause noticeable social or academic impairment.

#### **Prevalence**

Since 2003, the Centers for Disease Control (CDC) have used national survey data to monitor the number of children with ADHD (CDC, 2013). The largest of these surveys is the National Survey of Children's Health, which has been conducted every four years since 2003. Previous results from the 2003 and 2007 surveys found that 7.8 percent and 9.5 percent of U.S. children ages 4 to 17 years were diagnosed with ADHD in 2003 and 2007, respectively. A more recent study used data from the third National Survey of Children's Health, which was conducted between 2011 and 2012. The findings from this study provided information on ADHD diagnosis and treatment patterns, as well as the substantial impact that ADHD has on families. This study found that an estimated 11 percent of children and adolescents ages 4 to 17, or 6.4 million youth nationwide, have been diagnosed with ADHD (CDC; Visser et al., 2014). Kentucky was found to have the highest rate of ADHD in children, with almost 19 percent of children in Kentucky having been diagnosed with ADHD (Coyne, 2013). Over 11 percent of Virginia youth were diagnosed with ADHD, representing a population that has steadily risen over the last eight years as illustrated in Table 1 (CDC).

Table 1
Virginia Prevalence Rates of ADHD

2003	2007	2011
9.3%	10.2%	11.8%

Source: CDC, 2013.

ADHD is diagnosed more frequently in males than in females in the general population, with a ratio of approximately 2:1 in children and 1.6:1 in adults (APA, 2013). Females are more likely than males to present primarily with inattentive features (APA). Of high school students, almost 20 percent of boys and almost nine percent of girls had ADHD. Prevalence of ADHD is higher in households with parents who graduate from high school than in households with more or less education (Visser et al., 2014).

There has also been an increase in the overall rate of diagnosis. This increase is not without controversy. One physician believes the surge in diagnosis is merely a way to justify prescribing medication, which he calls "a national disaster of dangerous proportions" (Conners, as cited by Schwarz, 2013). Conversely, providers may be diagnosing ADHD more often because they have become more aware of the risks of untreated ADHD (Schwarz).

#### **Causes and Risk Factors**

As previously stated, the *DSM-5* categorized ADHD as a neurodevelopmental disorder (APA, 2013). Mounting evidence has demonstrated a neurological and a genetic basis for ADHD (AACAP, 2007). Studies in the past 20 years involving twins, adoptions, and molecular investigations suggest this genetic link. A child diagnosed with ADHD is more likely than one without ADHD to have family members with the disorder. The heritability of ADHD averages approximately 80 percent, rivaling the heritability factor for the trait of height (Barkley, 2006). In fact, according to the National Institutes of Health (NIH) one-third of fathers who have or had ADHD will have children who will be diagnosed with ADHD (National Institutes of Health, 2015).

Deficits in executive functioning in the frontal lobes of the brain are associated with the core features of ADHD (AACAP, 2007). Executive functioning serves to connect past experiences with present action. Essential functions such as planning, organizing, strategizing, and paying attention are all executive functions (NCLD, 2010). Brain imaging studies show differences between the structure and functioning in the areas of the brain responsible for executive functioning in individuals with ADHD as compared to brain images from individuals not diagnosed with ADHD (Bush, Valera, & Seidman, 2005; Castellanos et al., 2002; Sowell et al., 2003). A recent study revealed that those with ADHD had smaller brain volume in five subcortical regions, as well as an overall smaller brain volume (Hoogman et al., 2017). This phenomenon was greatest in children and less notable in adults.

Prenatal factors may also influence the likelihood that a child develops ADHD. Approximately 10 to 15 percent of youth with ADHD have been exposed to prenatal, perinatal, and postnatal

influencers. Mothers who smoke or drink during pregnancy are two and a half times more likely to have a child with ADHD than mothers who abstain from both (Rostain, 2012). Additional prenatal influencers to ADHD development include premature birth, maternal respiratory infections, maternal anxiety, and high levels of phenylalanine in the mother (Rostain). Postnatal factors include head trauma, brain hypoxia, tumors or infection in the central nervous system, seizures, lead poisoning, leukemia, pediatric acute lymphoblastic leukemia, strep, and, like in mothers, high levels of phenylalanine (Rostain).

A study conducted by the National Institute of Mental Health (NIMH) linked ADHD to changes in production of the brain chemical dopamine (2007). Evidence suggests the involvement of a gene that codes for a receptor protein that binds to dopamine. Children possessing a variant of this gene had an increased risk of ADHD (NIMH). The report indicated that this version of the dopamine D4 receptor gene, called the 7-repeat variant, accounted for approximately 30 percent of the genetic risk for ADHD, making it by far the strongest candidate gene implicated in the disorder (NIMH). Traits linked to the 7-repeat version may include novelty-seeking and impulsiveness (NIMH). Researchers are following up with studies on the relationship between cortex thickness and the cognitive features present in ADHD (NIMH).

A study done by Rostain (2012) found the following variants of seven genes correlate with ADHD:

- Serotonin HTR1B receptor
- Serotonin transporter
- Synaptosomal-associated protein 25 (SNAP 25)
- Dopamine B-hydroxylase
- Dopamine transporter,
- Dopamine D5 receptor
- Dopamine D4 receptor

The 7-repeat variant of the D4 receptor increases the risk of ADHD when joined by dopamine transporter (SLC6A3 10 repeat) and/or maternal exposure to smoking. Combining two of the factors increases the risk of ADHD by 2.5 to 3.0 times, and combining all three increases the risk to nine times (Rostain).

In addition to dopamine production, serotonin may affect the likelihood of ADHD in youth. A study presented to the Society for Neuroscience suggests that when serotonin receptors are disrupted, mice develop aggression and impulsivity (Mientka, 2013). When scientists reintroduce those receptors in the mice, impulsivity is curbed but aggression persists (Nautiyal et al., 2013). Although this does not yet point to a treatment, it does begin to explain why some youth act negatively. A child with less control in his prefrontal cortex, which helps decision-making, has a reason for his reduced self-control (Mientka).

Environmental risks include abuse, poverty, or exposure to violence. A study of children with ADHD showed that most of ADHD development is genetically driven, but in certain cases, ADHD may also result from very early adverse childhood experiences (Webb, 2013). Children who have experienced negative experiences early in life are diagnosed sooner than those with

only genetic connections. The associated impulsivity and inattention is more severe, while the hyperactivity is less severe than in those children without negative experiences (Webb).

#### Assessment

Careful assessment is critical to meeting the needs of youth with ADHD. A thorough and comprehensive assessment of ADHD includes gathering information from multiple sources, assessing functioning in multiple domains, ruling out alternative diagnoses, and eliminating comorbid conditions (AACAP, 2007). Qualified mental health professionals are the only individuals with the ability to diagnose and subsequently treat ADHD (NIMH, 2007). Qualified mental health professionals include child psychiatrists, psychologists, developmental/behavioral pediatricians, behavioral neurologists and, in some cases, clinical social workers (NIMH).

A diagnosis of ADHD requires the symptoms affect multiple domains of the youth's life (APA, 2013). Accordingly, it is important to assess the youth's functioning at home, school, day care or in other settings (AACAP, 2007). Assessment should involve the youth, the parents/caregivers, and the youth's teachers. A multimodal strategy should be used to assess for the presence of ADHD. The necessary components of a comprehensive assessment of ADHD include the following:

- A complete history and physical examination involving the patient and one or more parents or primary caregivers;
- Contact with teachers or caregivers familiar with the child's functioning and behaviors;
- A thorough investigation of co-occurring disorders or other conditions that may be the primary cause or are contributing to the patient's presentation (French, 2015).

Structured clinical interviews should be used to determine the presence, duration, and age of onset for each symptom. Validated behavior rating scales should also be completed by parents and teachers to compare the youth's behavior to established normative behavior (AACAP). Onset should be before age 12 and follow a chronic course (APA). Although most parents notice inattention, hyperactivity, and impulsivity before their child is school-age, these symptoms may go unnoticed until the child runs into problems at school (NIMH, 2003). An alternative diagnosis should be considered if the majority of symptoms began after age 12, there are patterns of remission, or symptoms are present in only one setting (e.g., at home or at school).

Comorbid conditions should also be assessed during an evaluation for ADHD. Comorbid disorders to ADHD include language deficits, impaired motor development, and social development delays. While these delays are not mutually exclusive of ADHD, they are frequently seen in youth with ADHD. Children may also show a lower tolerance to frustration, they may be irritable, or they may have mood lability (extreme fluctuations in mood) (APA, 2013). The presence of a comorbid disorder will influence treatment planning, especially pharmacological interventions. The diagnosis that is the most impairing to the child is usually the initial focus of treatment. In instances of disruptive behavior, the clinician must determine whether the disruptive behavior is the primary diagnosis or is secondary to ADHD (AACAP, 1994). If ADHD is the primary cause, it must be diagnosed and treated in most instances so that the secondary disruptive behavioral disorder can also be successfully addressed (AACAP). In

other cases, the disruptive behaviors can be treated first. Similarly, other comorbid disorders, such as anxiety and depression, can be treated successfully either concurrently or before or after the treatment of ADHD.

Before diagnosing a child with ADHD, the clinician should rule out other potential reasons for the child's behavior. Behaviors that mimic ADHD may be the result of a sudden change in the child's life, undetected seizures, a middle ear infection causing hearing problems, medical disorders affecting brain functioning, a learning disability, communication disorders, anxiety, or depression (NIMH, 2003). Children should be referred to a specialist for additional testing if seizures or other medical disorders are suspected (AACAP, 2007). A qualified professional should administer tests of intelligence and learning achievement to rule out a cognitive impairment or a learning disability as the possible cause of ADHD-like symptoms (AACAP). Adolescents may be difficult to diagnose and, because ADHD is often diagnosed in younger children, clinicians and parents need to look for previous signs or symptoms of ADHD present earlier in the adolescent's life. Clinicians should also be aware of signs of comorbid or alternative diagnoses including substance abuse, depression, and anxiety (AAP, 2011).

Table 2 outlines evidence-based assessment tools for ADHD.

Table 2
Evidence-based Assessment Tools for ADHD

Name of Measure	Measure Type
NIMH Diagnostic Interview Schedule for Children-IV	Structured diagnostic interview
Schedule of Affective Disorders and Schizophrenia for School- Aged Children, Present and Lifetime Version (K-SADS-PL)	Structured diagnostic interview
Anxiety Disorders Interview Schedule (ADIS C/P)	Structured diagnostic interview
ADHD Rating Scale-IV	Behavior rating scales
Child Behavior Checklist/Teacher Report Form	Behavior rating scales
Conners Rating Scale (Parent, Teacher, and Adolescent Self-Report Scales)	Behavior rating scales
Disruptive Behavior Disorders Rating Scale (Parent, Teacher, Youth Report Scales).	Behavior rating scales
Home Situations Questionnaire-Revised (School and Home Situations Questionnaire-Revised)	Behavior rating scales
The Vanderbilt ADHD Teacher Rating Scale (VADTRS) and Vanderbilt ADHD Parent Rating Scale	Behavior rating scales

## Comorbidity

According to the National Institute of Mental Health (2000), ADHD is not typically an isolated disorder and comorbidities may complicate research studies and diagnoses. For youth with ADHD, oppositional defiant disorder (ODD) co-occurs in approximately half of children with the combined presentation and about a quarter with the predominantly inattentive presentation (APA, 2013). Conduct disorder co-occurs in about a quarter of children or adolescents with the combined presentation, depending on age and setting (APA). Most children and adolescents with disruptive mood dysregulation disorder (recently added to the *DSM-5*) have symptoms that also meet criteria for ADHD. Specific learning disorder commonly co-occurs with ADHD. Anxiety disorders and major depressive disorder occur in a minority of individuals with ADHD but more often than the general population. Other disorders that may co-occur with ADHD include obsessive-compulsive disorder, tic disorders, and Autism Spectrum Disorder (ASD). The *DSM-5* allows for a comorbid diagnosis of ADHD with ASD (APA, 2013). This combination was not allowed in previous versions of the *DSM*. Nearly 30 percent of children with ASD also have ADHD (Kennedy Krieger Institute, 2013).

ADHD is associated with cognitive problems in attention, executive function, and memory tests. However, these tests cannot serve as a diagnostic tool due to their lack of sensitivity. Suicidal tendencies are higher in young adults who have ADHD and mood, conduct, and/or substance abuse disorder (APA, 2013).

New studies show that children with ADHD symptoms may run the risk of obesity and physical inactivity once they reach adolescence. The study extends previous research that exercise improves behavior in youth with ADHD to identify a long-term link between physical inactivity and inattention (Khalife, Kantomaa, & Glover et al., 2014).

#### **Treatments**

ADHD is a chronic disorder; therefore, management of symptoms is the goal of treatment. Treatment must be provided over long periods to assist those with ADHD in the ongoing management of their disorder. A variety of treatments should be used to treat ADHD. Foremost is education of the family and school staff about ADHD and its management. A comprehensive treatment plan involving the youth, parents, and school personnel should be implemented to address all relevant areas of impairment. Current research suggests that a combination of behavioral and pharmacological treatments is the most effective (AACAP, 2007; Pelham & Fabiano, 2008; Chorpita et al., 2011).

Effective treatment includes developing and utilizing an appropriate educational program; behavior modification; parent, child, and teacher education; counseling; and medication (Children and Adults with Attention Deficit Disorders [CHADD], 2001). Parents also need to advocate for their children in academic settings. Children with ADHD may be eligible for special educational services in the public schools under both the Individuals with Disabilities in Education Act (IDEA: Public Law 101-476) and Section 504 of the Rehabilitation Act of 1973 (Public Law 93-112). IDEA governs special education requirements and Section 504 provides for reasonable accommodations for children with disabilities (Gephart, 2002). Parental involvement can help to optimize positive outcomes.

Treatments are outlined in Table 3 and in the paragraphs that follow.

Table 3

Summary of Treatments for ADHD

What Works	
Behavioral classroom management (BCM)	BCM uses contingency management strategies, including teacher-implemented reward programs, token systems, time-out procedures, and daily report cards (DRCs). Clinicians or parents may work in consultation with teachers to develop a classroom treatment plan.
Behavioral parent training (BPT)	BPT teaches the parent to implement contingency management strategies similar to BCM techniques at home.
Intensive behavioral peer intervention (BPI)	Intensive BPI is conducted in recreational settings, such as summer treatment programs (STPs). STPs have demonstrated effectiveness and are considered well-established. However, STPs are less feasible to implement than other evidence-based practices.
Stimulant: d-Amphetamine	Short-acting: Adderall, Dexedrine, DextroStat Long-acting: Dexedrine Spansule, Adderall XR, Lisdexamfetamine
Stimulant: Methylphenidate	Short-acting: Focaline, Methylin, Ritalin Intermediate-acting: Metadate ER, Methylin ER, Ritalin SR, Metadate CD, Ritalin LA Long-acting: Concerta, Daytrana patch, Focalin XR
Serotonin and norepinephrine reuptake inhibitor (SNRI): atomoxetine	Atomoxetine is unique in its ability to act on the brain's norepinephrine transporters without carrying the same risk for addiction as other medications.
What Does Not Work	
Cognitive, psychodynamic, and client-centered therapies	Traditional talk therapies and play therapy have been demonstrated to have little to no effect on ADHD symptoms. ADHD is best treated with intensive behavioral interventions in the youth's natural environments.
Office-based social skills training	Once-weekly office-based training, either one-on-one or in a group setting, have not led to significant improvement in social skills. (However, intensive group social skills training that uses behavioral interventions, such as STPs, are considered well-established.)
Dietary interventions	Interventions include elimination of food additives, elimination of allergens/sensitivities, and use of nutritional supplements.
Antidepressants	These include bupropion (Wellbutrin), imipramine (Tofranil), nortriptyline (Pamelor, Aventil), clonidine (Catapres) and guanfacine (Tenex).

Sources: AACAP, 2007; Pelham & Fabiano, 2008; Pelham & Hoza, 1996

## Psychological Treatments

Behavior therapy is the psychological treatment of choice for ADHD (Pelham & Fabiano, 2008; AACAP, 2007). One behavior therapy that has consistently worked is behavioral classroom management. Another behavior therapy treatment approach that has been supported by research is behavioral parent training (Pelham & Fabiano).

Behavior therapy uses contingency management strategies (e.g., point/token reward systems, timeout, response cost) to reinforce appropriate behavior and reduce unwanted behaviors. Contingency management strategies employ reward systems that are designed to provide reinforcements to increase desired behaviors, including following directions, attentiveness, or turn-taking. Rewards systems can take many forms, including, but not limited to, points, stickers, poker chips, or other tokens that can be traded for small prizes or special privileges. Careful consideration must be taken to ensure that rewards are age appropriate and salient to the youth. Young children may benefit more from tangible rewards, while adolescents may appreciate point systems to earn special privileges. Response-cost programs remove a reinforcer, or desired object or activity, when an undesirable behavior occurs in order to reduce that behavior. This can include loss of points or tokens from a reward system, loss of privilege, or time-out. Timeouts—also called "time out from reinforcement"—are a form of response-cost used to decrease undesirable behaviors. For time-outs to be effective, they must remove children from a desirable activity (television, video games, contact with other children) and place them in a neutral location. Behavioral intervention systems can be put in place both in the classroom and at home (Evans et al., 2005; Barkley, 2000).

The following essential steps outline a behavior management program:

- 1. Specify acceptable and unacceptable behaviors.
- 2. Choose an unacceptable behavior to change, and explain the positive actions in observable and measurable terms.
- 3. Identify motivational items to help the youth stay on track.
- 4. Utilize an accounting system to measure rewards, punishment, and progress.
- 5. Draw up a contract, and renegotiate as success becomes more frequent (Rostain, 2012).

Through behavior management, parents, guardians, and other adults should focus on positive behaviors and seek to find the youth behaving properly as much as possible (Rostain, 2012). This will help shift the youth's energy to being good, and thus reduce the focus on poor behaviors.

#### Behavioral Classroom Management

Behavioral classroom management (BCM) has received the most support of any psychological treatment for youth with ADHD (Pelham & Fabiano, 2008). BCM are teacher-implemented behavior modification strategies. Effective classroom management strategies include reward programs, point systems, and time-outs. The Daily Report Card (DRC) (Jurbergs & Kelley, 2008) is another effective classroom management strategy included in many of the studies reviewing BCM (Pelham & Fabiano; Pelham, Wheeler, & Chronis, 1998). The DRC provides feedback to youth, parents, and mental health professionals about target behaviors occurring in the classroom, and bridges BCM and home-based interventions.

#### **Behavioral Parent Training**

Behavioral parent training (BPT) teaches parents behavior management and discipline skills to extend treatment from the therapist's office to the home in order to address a wide array of problematic behaviors. The behavioral techniques used in BPT programs include positive reinforcement, time-out from reinforcement, and/or response cost techniques. BPT takes many different forms, ranging from brief problem-focused programs to more extensive programs lasting 18 sessions or more in individual or group settings. The most frequent training method involves providing verbal instruction through one-on-one discussion with parents, followed by educational reading materials (Moreland et al., 1982). BPT has been shown to be effective in improving problematic child behavior and negative parent-child interactions (Chronis et al., 2004).

## Pharmacological Treatments

Pediatricians, family physicians, specialized psychiatrists, and child psychiatrists most frequently prescribe stimulant medications for the treatment of ADHD. Studies have found a significant majority of children with ADHD derive benefits from these medications and that they are effective at reducing ADHD symptoms in the short-term (AACAP, 2007). Medications for ADHD act on dopaminergic pathways in the prefrontal cortex, striatum, and nucleus accumbens (Sauer, Ring, & Witcher, 2005) and increase the availability of dopamine in the brain.

Two frequently prescribed stimulant medications for ADHD are methylphenidate (i.e., Ritalin or Concerta) and amphetamines (e.g., Adderall) (National Institute of Drug Abuse [NIDA], 2014). The tolerability and safety of stimulant medications are comparable, with all medications demonstrating similar side effects, including effects on cardiovascular functioning, sleep disturbance, appetite suppression, and anxiety (Wernicke & Kratochvil, 2002). The major drawback of stimulant medications is the lack of selectivity on the subcortical regions upon which they act. There is a salient potential for abuse of stimulant medications due to their effects on the brain (Bymaster et al., 2002; Wee & Woolverton, 2004). As a result, methylphenidate and dexamphetamine are listed as Schedule II drugs with the U.S. Food and Drug Administration (FDA).

The FDA has also approved atomoxetine, a medication for treating ADHD that is not a stimulant (NIMH, 2003). Atomoxetine acts specifically on the prefrontal cortex to increase levels of dopamine and norepinephrine, which leads to improved executive functioning and reduced ADHD symptoms. Atomoxetine is unique in its ability to act on norepinephrine transporters in the prefrontal cortex without acting on striatum or nucleus accumbens regions of the brain (Bymaster et al., 2002; Wee & Woolverton, 2004). These benefits may also help reading in youth with dyslexia (Rostain, 2012).

The side effects of atomoxetine are similar to those of stimulant medications but are milder (Rostain, 2012). Despite side effects, atomoxetine is considered well-tolerated in most children and adults (Spencer et al., 1998). An examination of four clinical trials reported to the FDA showed the percentage of overall discontinuation of use due to adverse events was 3.8 percent (Wernicke & Kratochvil, 2002). Other medications for ADHD, such as methylphenidate and dexamphetamine, act on the entire norepinephrine and dopamine regions, including the striatum

and nucleus accumbens. Increases in dopamine in these regions of the brain activate the brain's reward system, which heightens the potential for abuse. Because atomoxetine does not act on these regions, it does not carry the same risk of addiction and is not a scheduled drug (Sauer, Ring, & Witcher, 2005; Rostain, 2012). Atomoxetine may be beneficial in those youth with anxiety and tic disorders (Rostain).

In 2009, alpha-adrenergic agonists, which include Clonidine and Guanfacine, were approved by the FDA for treatment of ADHD. This class of medications is frequently used when either symptoms do not respond to other approved medications (stimulants or atomoxetine) or the side effects of other medications are intolerable (e.g., the tics associated with stimulants) (Cruz, 2010; APA 2007). Alpha-adrenergic agonists help reduce irritability, over-arousal, explosiveness, and emotional lability in youth with ADHD (Rostain, 2012). Agonists are commonly used in conjunction with stimulants to treat ADHD, and are commonly used when there is a comorbid diagnosis of oppositional defiant disorder, Tourette disorder, or aggressive/impulsive behavior (Sallee, 2008). Guanfacine has shown to be an effective treatment for ADHD, but only in the short-term in children six to 12 years old (Bernknopf, 2011). The use of alpha-adrenergic agonists like Guanfacine has not been extensively tested and regular monitoring is recommended

#### **Unproven Treatments**

There is a long list of other interventions for the treatment of ADHD, including dietary replacement, exclusion, or supplementation; various vitamin and mineral regimens; various types of talk therapy; and perceptual stimulation. Treatment approaches that were tested and found to have no support in recent studies include client-centered therapy, self-control training, skill development, and the combination of parent management training and self-verbalization (AACAP, 2007). It is important, however, to note that some of these treatments may offer benefits to the accompanying symptoms of ADHD, so further study is needed (Chorpita & Daleiden, 2007).

There is much anecdotal evidence on the effects of diet on ADHD. Unfortunately, many studies on diet lack the rigorous scientific methods necessary to draw conclusions about their efficacy. Several foods are mentioned as possible triggers, particularly casein (derived from milk). More recently, gliadin (derived from wheat gluten) has been frequently cited (Lilienfeld, 2005). There are also studies linking ADHD to certain food sensitivities. Some of the dietary elimination strategies showed intriguing results, suggesting the need for future research. One dietary study determined that food additives might have an impact on a child's hyperactivity level (Warner, 2004). Treatments focusing on mineral supplementation also merit further study, but current data suggest that mineral supplementation is useful only when true deficiency has been demonstrated. Although these approaches have generated considerable interest and there are studies exploring various treatment strategies, the research does not currently support their use.

Additional unproven treatments for ADHD include interactive metronome training (IM), wherein a patient synchronizes hand and foot exercises to audible tones. A study at Michigan State University found this beneficial for some children (Shaffer et al., 2001). The study was small, with 56 participants, 19 of whom received IM training, and all were male between ages six and twelve.

A study by Sonuga-Barke and his colleagues (2013) questioned the efficacy of neurofeedback as a treatment for ADHD and suggested that further study is needed to support it. However, a letter to the editor of the *American Journal of Psychiatry* (Arns & Strehl, 2013) questioned the method of comparison and resulting statistical analysis. As a result, neurofeedback is still yet-unproven, but may become an appropriate treatment for ADHD in the future, if researchers can provide more empirically-based data.

Antidepressant medications are sometimes prescribed "off-label" for the treatment of ADHD, meaning they have not been approved by the FDA for the treatment of ADHD. These include Bupropion, Imipramine, and Nortriptyline (AACAP, 2007).

#### **Cultural Considerations**

Research also suggests that even though ADHD is not more prevalent in different ethnicities, the rate of diagnosis is different. This may be attributable to different diagnostic practices, cultural variation in attitudes, and/or differing interpretations of children's behaviors (APA). Caucasian youth are more likely to be diagnosed and receive treatment for ADHD (Eiraldi et al., 2006). The lack of culturally sensitive assessment tools and the prevalence of stereotypes also play a role in under-diagnosis or misdiagnosis (Eiraldi et al.). As a result, it is critical that health care professionals receive training in multicultural mental health issues to ensure proper diagnosis and treatment (Morgan et al., 2013). Recommendations include understanding how minority families perceive the youth's behavior, the use of culturally sensitive assessment methods, and education about the causes and treatment of ADHD, while maintaining respect for cultural beliefs.

#### Overview for Families

All children show inattention, distractibility, impulsivity, or hyperactivity, but children with ADHD show increasingly severe and frequent symptoms (AACAP 2013). The symptoms must begin before the age of 12, and they can continue into adulthood (APA, 2013).

A child with ADHD often shows some of the following:

- Trouble paying attention
- Inattention to details and makes careless mistakes
- Easily distracted
- Loses school supplies; forgets to turn in homework
- Trouble finishing class work and homework
- Trouble listening
- Trouble following more than one instruction at a time
- Blurts out answers
- Is impatient
- Fidgets or squirms
- Leaves seat and runs about or climbs excessively
- Seems "on the go"
- Talks too much and has difficulty playing quietly
- Interrupts or intrudes on others (AACAP, 2008)

ADHD may coexist in children with conduct disorder, anxiety disorder, depressive disorder, bipolar disorder, autism spectrum disorder, or learning disabilities (AACAP 2013; APA 2013).

A child with ADHD struggles with schoolwork and can experience increased failures when teachers and/or family do not recognize a health problem. Children with ADHD also struggle with friendships and can experience low self-esteem as a result. Therefore, a child with ADHD symptoms should have a comprehensive evaluation. Parents should ask their pediatrician or family physician to refer them to a child and adolescent psychiatrist, who can diagnose and treat this medical condition (AACAP, 2008).

Special education services in public schools may be available for children with ADHD. The Individuals with Disabilities in Education Act (IDEA) and the Rehabilitation Act provide special education accommodations and require public schools to offer certain services. Section 504 of the Rehabilitation Act of 1973 states any school receiving federal aid is required to provide a certain level of education to all children regardless of disability (National Resource Center, [NRC], 2012). Therefore, all children must be given the opportunity to participate in all academic and non-academic services offered by a school. A student qualifying for services under the Act must have a physical or mental disability that substantially impairs a "major life activity." In relation to ADHD, "major life impairments" include reading, thinking, concentrating, and communicating with others. Examples of accommodations include:

- Reducing the number of homework problems without reducing level or content of material
- Providing students with a quiet place to take exams or study
- Providing students with additional time on exams
- Providing the student with access to counseling services (NRC, 2012)

Students receiving these benefits must achieve at the same level as their peers and participate in all state-required assessments (NRC, 2012). Individual Education Programs (IEPs) ensure students are achieving short- and long-term educational goals.

## **Resources and Organizations**

## American Academy of Child & Adolescent Psychiatry (AACAP)

**ADHD Resource Center** 

http://www.aacap.org/AACAP/Families\_and\_Youth/Resource\_Centers/ADHD\_Resource\_Center/Home.aspx

#### **American Psychiatric Association (APA)**

ParentsMedGuide

http://www.parentsmedguide.org/

#### **Attention Deficit Disorders Association – Southern Region**

http://www.adda-sr.org/

#### **Centers for Disease Control and Prevention (CDC)**

Attention-Deficit/Hyperactivity Disorder

https://www.cdc.gov/ncbddd/adhd/

#### **Children and Adults with Attention Deficit Disorders (CHADD)**

http://www.chadd.org/

#### **U.S. Department of Education**

Identifying and Treating Attention Deficit Hyperactivity Disorder: A Resource for School and Home

https://www2.ed.gov/rschstat/research/pubs/adhd/adhd-identifying.html

## Virginia Resources and Organizations

#### Children and Adults with Attention Deficit Disorders (CHADD)

http://www.chadd.org/

Central Virginia Chapter

804-385-3139

Northern Virginia CHADD

24-Hour Information Line - 703-641-5451

CHADD of Tidewater

866-633-4871 (Toll free)

CHADD Shenandoah Valley Satellite

540-241-4754

#### **Parent Educational Advocacy Training Center**

www.peatc.org

#### Virginia Commonwealth University

Center for ADHD Research, Education, and Service http://www.adhd.vcu.edu/clinical-services/

#### **Virginia Department of Education**

Attention Deficit/Hyperactivity Disorder

http://www.doe.virginia.gov/special\_ed/disabilities/other\_health\_impairment/specific\_condit ions.shtml

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## Motor Disorders

#### Introduction

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#### Introduction

Motor disorders begin early in the developmental years and involve problems with movement. Children with motor disorders may be substantially delayed in reaching motor milestones (such as navigating stairs or tying shoes); they may make repetitive and driven movements (such as rocking); or they may have physical or verbal tics. As with other disorders, these behaviors cause impairment and result in negative physical and/or social consequences.

#### Recent Changes from the DSM-IV to the DSM-5

The American Psychiatric Association released the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*) in 2013 to replace the fourth text revision *DSM-IV-TR*. The *DSM-5* created a new subcategory called "Motor Disorders" under a new grouping called "Neurodevelopmental Disorders." In the *DSM IV-TR*, developmental coordination disorder, stereotypic movement disorder, and tic disorders were included under the cluster "Disorders Usually First Diagnosed in Infancy, Childhood, and Adolescence." Furthermore, *DSM-IV-TR* only specified that developmental coordination disorder was a motor skills disorder. In the *DSM-5*, these disorders are now reclassified under the motor disorders subcategory. Tic disorders include Tourette disorder (also called Tourette syndrome), persistent (chronic) motor or vocal tic disorder, provisional tic disorder, other specified tic disorder, and unspecified tic disorder (APA, 2013).

A significant change was made to the tic disorders category. In the *DSM IV-TR*, a tic disorder diagnosis required that the youth did not have a period of more than three months in which he or

she was tic-free. The *DSM-5* does not have this requirement in the criteria. This is because tics may "wax and wane" in their occurrence and frequency (APA, 2013).

In the future, more evidence supporting treatments of disorders with *DSM-5* classifications will be available as clinical studies utilizing *DSM-5* criteria are conducted. As a result, this *Collection* will reference studies that utilize *DSM-IV* diagnostic criteria to explain symptoms and treatments.

## **Categories**

Unless otherwise cited, information in the section "Categories" is taken from the DSM-5 (APA, 2013). Categories of motor disorders as defined in the DSM-5 are outlined in Table 1.

Table 1

Motor Disorders Affecting Children & Adolescents

Disorder		Description	
Developmental coordination disorder		Coordinated motor skills, both developing and executing, is substantially below expectations based on age and education. Symptoms include clumsiness and slow and inaccurate motor skills. Onset is early in development.	
Stereotypic movement disorder		Includes repetitive, driven, and purposeless motor behavior like shaking, rocking and hitting oneself. Onset is early in development.	
Tic disorders	Tourette disorder	Both vocal and motor tics for a period of more than one year, but not necessarily concurrently. The tics may wax and wane in frequency. Onset is prior to age 18.	
	Persistent (chronic) vocal or motor tic disorder	Single or multiple motor tics or verbal tics occurring multiple times daily or almost daily for more than one year. Onset before age 18. Both motor and verbal tics cannot be present for this diagnosis	
	Provisional tic disorder	Single or multiple vocal and/or motor tics present for less than one year. Onset before age 18.	
	Other specified tic disorder	Applies to symptoms characteristic, but not meeting the diagnostic criteria, of a tic disorder or any disorder in the neurodevelopmental disorder categories. The clinician will specify why the tic disorder presented.	
	Unspecified tic disorder	Applies to symptoms characteristic, but not meeting the diagnostic criteria, of a tic disorder or any disorder in the neurodevelopmental disorder categories. The clinician will not specify the reason for the tic disorder.	

Source: APA, 2013.

## **Developmental Coordination Disorder**

Developmental coordination disorder presents early in development. A child with developmental coordination disorder develops and executes coordinated motor skills substantially below expectations based on the child's age and education. A child may be clumsy or his or her motor skills may be slow, inaccurate, or both.

Young children with developmental coordination disorder may be delayed in reaching motor milestones such as climbing stairs and buttoning shirts. They may reach these milestones, but do so with awkward, slow, or imprecise movements when compared with their peers. Alternatively, older children may show slow speed or inaccurate movements with skills like handwriting, puzzles, model building, ball games, or self-care. Only when these slow, awkward movements interfere with performing or participating in daily activities can a developmental coordination disorder diagnosis be given. Also, the child must be assessed for any visual impairments and neurological disorders before they are diagnosed with developmental coordination disorder. Although onset must be early, most diagnoses normally do not occur prior to age five, when a child enters school. Problems remain in about 50 to 70 percent of children diagnosed even after coordination improves.

## Stereotypic Movement Disorder

Stereotypic movement disorder, like developmental coordination disorder, presents early in a child's development. Symptoms include repetitive and driven motor behaviors like shaking, rocking, and hitting oneself. For a confirmed case of stereotypic movement disorder, these behaviors cannot be attributed to a substance or other neurological disorder. Typically developing children can stop repetitive motions when distracted or given attention, but children with motor disorders cannot stop the motions or will restrict their movements through other means such as sitting on their hands or wrapping their arms in their clothing.

There are two types of classifications for stereotypic movement disorder: "with self-injurious behavior" and "without self-injurious behavior." Children with the classification "with self-injurious behavior" engage in movements that could be harmful to their bodies (e.g. lip biting, head banging, or eye poking). Conversely, children with the classification "without self-injurious behavior" engage in movements that are not physically harmful to themselves (e.g. body rocking, arm flapping, or head nodding).

In terms of body location, stereotypies frequently involve arms, hands, or the entire body, rather than the more common tic locations of the eyes, face, head, and shoulders. Stereotypies are more fixed, rhythmic, and prolonged in duration than tics, which (except for the occasional dystonic tic) are brief, rapid, random, and fluctuating. Also in contrast to tics, stereotypies are not associated with premonitory urges, preceding sensations, or an internal desire to perform. Both occur during periods of anxiety, excitement, or fatigue, but stereotypic movements are also common when the child is engrossed in an activity. Tics and stereotypic movements are both reduced by distraction, but the effect on stereotypic movements is more instantaneous and dramatic (D. Oswald, personal communication, September 18, 2017; Singer, 2009).

More males than females present with stereotypic movement disorder in childhood (Gluck, 2016). In children who develop complex motor stereotypies, approximately 80 percent exhibit symptoms before 24 months of age, 12 percent between 24 and 35 months, and 8 percent at 36 months or older. Simple stereotypic movements are often present in typically developing children under the age of three. Only when these movements persist or become a hindrance to development are they considered a disorder.

Stereotyped or repetitive motor movements are also a distinguishing feature of autism spectrum disorder (ASD). Differential diagnosis of stereotypic movement disorder and ASD involves consideration of the individual's social communication and reciprocity. Deficits of social communication and reciprocity are generally absent in stereotypic movement disorder. When ASD is present, stereotypic movement disorder is diagnosed only when there is self-injury or when the stereotypic behaviors are sufficiently severe to become a focus of treatment.

#### **Tic Disorders**

Tics are involuntary movements, sounds, or words that are sudden, rapid, recurrent, and nonrhythmic. *DSM-5* uses the following terminology to describe tics:

- Vocal tics (e.g., repeated throat clearing or spoken words)
- Motor tics (e.g., repeated blinking or arm movements)
- Simple tics (a short, brief noise or movement)
- Complex tics (a vocalization, noise, or movement that appears to take effort, like a spoken word, a complex sound, or raising one's arm up over one's head)

Tics vary from other childhood movement disorders in a few ways. They have varied severity, their movement characteristics change over time, the movements are temporarily suppressible, and they are associated with sensory phenomena (Cohen, Leckman, & Bloch, 2013).

There are five distinct tic disorders in the *DSM-5*: Tourette disorder, persistent (chronic) motor or vocal tic disorder, provisional tic disorder, other specified tic disorder, and unspecified tic disorder. Diagnosis varies, depending upon the particular kind of tic-related motor disorder.

<u>Tourette disorder</u> is the most well-known tic disorder, largely because of its depictions in movies and television shows, but it is relatively uncommon. Symptoms for Tourette disorder must be present before age 18, and both vocal and motor tics must be present. The tics may vary over time, but must persist for over one year since the onset of the original symptoms. Age of onset can be anywhere between the ages of two and 21, with the most severe tics occurring between the ages of 10 and 12.

<u>Persistent (chronic) motor or vocal tic disorder</u> involves one or more motor or vocal tics, but cannot include both. If both motor and vocal tics occur, the child should be screened for Tourette disorder. The tics may vary in frequency, but must persist for more than one year after onset. Tics must begin before age 18 and cannot be attributable to another disorder or substance.

<u>Provisional tic disorder</u> is diagnosed when tics are present for less than one year. There can be one or more tics, which can include motor and/or vocal tics. Tics cannot be attributable to

another disorder or substance. Additionally, the child cannot have been diagnosed with Tourette disorder or persistent (chronic) motor or vocal tic disorder in the past.

Other specified tic disorder applies to cases in which there are symptoms characteristic of a tic disorder that cause significant distress or impairment but do not meet the full criteria for a tic disorder or for any of the disorders in the neurodevelopmental disorders diagnostic class. This diagnosis is used in situations in which the clinician chooses to specify the reason that the criteria are not met for a tic disorder or for a specific neurodevelopmental disorder. Diagnosis is followed by the specific reason (e.g., "with onset after age 18 years"). Because this subcategory is not common, the *Collection* will focus on more prevalent motor disorders.

<u>Unspecified tic disorder</u> also applies to cases in which there are symptoms characteristic of a tic disorder that cause significant distress or impairment but do not meet the full criteria for a tic disorder or for any of the disorders in the neurodevelopmental disorders diagnostic class. However, this diagnosis is used in situations in which the clinician chooses not to specify the reason that the criteria are not met for a tic disorder or for a specific neurodevelopmental disorder. It includes presentations in which there is insufficient information to make a more specific diagnosis. Because this subcategory is not common, the *Collection* will focus on more prevalent motor disorders.

#### **Prevalence**

Table 2 discusses the prevalence of motor disorders.

Table 2
Prevalence of Motor Disorders

Disorder	Prevalence		
Developmental coordination disorder	<ul> <li>In children ages 5 to 11: 5% – 6%</li> <li>In children age 7: 1.8% are diagnosed with severe developmental coordination disorder, and 3% with probable developmental coordination disorder</li> <li>Males are affected more than females, with a ratio of between 2:1 and 7:1</li> </ul>		
Stereotypic movement disorder	<ul> <li>Simple movements (e.g., rocking) are common in young, developing children</li> <li>Complex stereotypic movements are much less common and exhibited in 3% – 4% of children</li> <li>Among individuals with intellectual disability, 4% – 16% engage in stereotypy and self-injury</li> <li>Among individuals with intellectual disability living in residential facilities, 10% – 15% may have stereotypic movement disorder with self-injury</li> </ul>		
Tourette disorder	<ul> <li>0.3% – 0.8% of school-age children</li> <li>Estimated that there are 3 per 1,000 of clinically identified cases in the U.S.</li> <li>Males are affected more than females, with a ratio of between 2:1 and 4:1</li> </ul>		
	t data available about the prevalence of persistent (chronic) motor or vocal tic all tic disorder, other specified tic disorder, or unspecified tic disorder.		

Source: APA, 2013.

#### **Causes and Risk Factors**

Underlying causes for the development of motor disorders are not well understood (United States National Library of Medicine, 2015). However, as with many psychological disorders, the evidence suggests that numerous factors, such as genetic vulnerability, learning, and environment, may contribute to the development of these disorders.

Studies of families suggest the presence of genetic underpinnings in the development of tic disorders. For example, relatives of individuals with Tourette disorder are 10 to 15 percent more likely to develop the disorder, and 15 to 20 percent more likely to have another tic disorder. These risk levels are significantly higher than in the general population. Studies of the human genome have identified specific genes thought to be related to Tourette disorder (Woods, Flessner, & Conelea, 2008). Studies have also shown that 25 percent of youth with stereotypic motor disorder have an affected relative (Mills & Hedderly, 2014). There is also likely to be a family history of obsessive tendencies often in the form of counting rituals.

There is also reason to believe that learning factors are significant in the development and maintenance of motor disorders. In stressful situations, for example, youth can develop the urge to trigger their tics or to self-injure. After the tic or self-injury becomes habitual, all similar situations may elicit the same response. These situations may, in turn, elicit an urge to perform the habit. Youth with motor disorders report an uncomfortable urge that is satisfied by the tic or self-injury. The satisfaction or reduction of the urge may reinforce the habit and thus increase the likelihood that the youth will repeat the behavior.

Environmental factors have also been implicated in the development of motor disorders. Developmental coordination disorder may be caused by prenatal exposure to alcohol, and it is often associated with preterm and children with a low birth weight (APA, 2013). Stereotypic movement disorder is frequently seen in socially isolated children who tend to self-stimulate, which may progress to stereotypic movements and even repetitive self-injury (APA). There have also been cases in which individuals who suffered from a traumatic head injury (e.g. concussion) had symptoms that mimic those seen in of stereotypic motor disorder (United States National Library of Medicine, 2015).

#### **Assessment**

Assessments of motor disorders vary slightly by the type of motor disorder. Typically, physicians obtain information about a motor disorder from a developmental and medical history, physical examination, school report, and individual assessment (APA, 2013). Assessment of tic disorders should include a medical examination to rule out conditions that can mimic tic disorders, such as behaviors related to allergies, eye problems that mimic tics, and stereotypic movement disorders (Woods, Piacentini, & Himle, 2007). Other medical conditions that may cause tics, such as Huntington's disease or post-viral encephalitis, must also be considered prior to diagnosing a motor disorder (APA).

Screening, followed by more in-depth assessment, is critical to accurate diagnosis due to the comorbidity that occurs frequently in youth with motor disorders. The Schedule for Affective Disorders and Schizophrenia-Children's Version (K-SADS) and the Anxiety Disorders Interview

for *DSM-IV* Child Version (ADIS-C) are semi-structured diagnostic interviews that have demonstrated strong psychometric characteristics (Chorpita & Southam-Gerow, 2006).

Suggested assessment tools for motor disorders are listed in Table 3.

Table 3
Suggested Assessment Tools

Name of Measure	Measure Type	Who Completes	Data Generated
Schedule for Affective Disorders and Schizophrenia – Children's Version (K-SADS)	Clinical interview	Clinician with youth and parent	Diagnosis
Anxiety Disorders Interview Schedule for <i>DSM-IV</i> – Child Version (ADIS-C)	Clinical interview	Clinician with youth and parent	Diagnosis
Yale Global Tic Severity Scale (YGTSS)	Clinician rating scale	Clinician	Symptom rating
Motor tic, Obsessions and compulsions, Vocal tic Evaluation Survey (MOVES)	Self-report rating scale	Parent or youth	Symptom rating
Repetitive Behavior Scale – Revised (RBS-R)	Caregiver rating scale	Parent or caregiver	Symptom rating
Motor Severity Stereotypy Scale (MSSS)	Caregiver rating scale	Parent or caregiver	Symptom rating
Tic Self-Report Scale	Self-report rating scale	Parent or youth	Symptom rating
Tourette Disorder Scale	Self-report rating scale	Parent or youth	Symptom rating
Parent Tic Questionnaire (PTQ)	Self-report rating scale	Parent or youth	Symptom rating
Child Tourette Disorder Impairment Scale – Parent Version	Self-report rating scale	Parent or youth	Symptom rating
Tourette Syndrome Severity Scale (TSSS)	Clinician rating scale	Clinician	Social impairment
Tourette Syndrome Global Scale (TSGS)	Clinician rating scale	Clinician	Symptoms and comorbidity

Sources: Chorpita & Southam-Gerow, 2006; Woods et al., 2006; Woods, Piacentini, & Himle, 2007; Woods, Flessner, & Conelea, 2008; Murphy et al., 2013; Harris et al., 2016; & Di Renzo et al., 2017.

#### **Developmental Coordination Disorder**

For developmental coordination disorder, it is important to recognize that symptoms may be confused with those of other conditions. There are four criteria that must be met for a diagnosis of developmental coordination disorder:

- 1. The child shows delays in reaching motor milestones;
- 2. The condition significantly interferes with activities of daily living and/or academic performance;
- 3. The symptoms begin early in the child's life; and
- 4. Difficulties with motor skills are not better explained by intellectual disability, visual impairment, or brain disorders (Harris, Mickelson, & Zwicker, 2015).

## Stereotypic Movement Disorder

It can be difficult to distinguish stereotypic movement disorder from symptoms of other disorders such as autistic spectrum disorder, intellectual disabilities, genetic syndromes, and sensory impairment. A tailored assessment is critical in order to define a precise developmental profile and to avoid misdiagnosis (Cardona et al., 2016). While there are no assessments that are specific for the diagnosis of this particular disorder, the Motor Severity Stereotypy Scale (MSSS) and the Repetitive Behavior Scale-Revised (RBS-R) can be used to assess the stereotypies (Cardona et al.). The MSSS is a five-item caregiver questionnaire in which the parent rates the child's motor stereotypies with regard to the motor severity by rating the number, frequency, intensity, and interference of stereotypies and the global impairment during the past few days (Harris et al., 2016). The RBS-R is a caregiver questionnaire that captures the breadth of repetitive behaviors in children with autism spectrum disorders. It consists of 43 items, rated on a four-point Likert scale ranging from "behavior does not occur" to "behavior occurs and is a severe problem," where higher scores indicate frequent dysfunctional behaviors (Di Renzo et al., 2017).

#### Tic Disorders

In conjunction with a thorough medical examination, a structured or semi-structured interview can be particularly helpful in gathering information about the expression of tics, including frequency, location and nature of the tic, complexity, controllability, intensity, level of distress, and temporal stability (Woods, Piacentini, & Himle, 2007). One such clinical interview is the Yale Global Tic Severity Scale (YGTSS), which can be administered in 15 to 30 minutes. This assessment helps to gather information about tic topography, symptom severity, and impairment (Woods et al.). Another assessment is the Premonitory Urge for Tics Scale (PUTS), a brief self-report measure for use with children age ten and older to measure awareness of tic-related premonitory urges (Woods, Flessner, & Conelea, 2008). Two assessment tools for Tourette disorder are Tourette Syndrome Severity Scale (TSSS), which weighs Tourette disorder social impairment, and Tourette Syndrome Global Scale (TSGS), which measures tics and comorbid problems (Murphy et al., 2013).

#### Comorbidity

Youth with motor disorders frequently experience other kinds of problems (Scahill, Sukhodolsky, & King, 2007; Woods et al., 2006; Woods, Piacentini & Himle, 2007).

ADHD is the most frequent coexisting condition in youth with developmental coordination disorder, with about 50 percent co-occurrence. Other disorders that commonly co-occur with developmental coordination disorder are autism spectrum disorder (ASD), disruptive and emotional behavior problems, speech and language disorder, and specific learning disorder, especially with reading and writing (APA, 2013).

Stereotypic movement disorder has been associated with children who have intellectual disabilities, including those with ASD (Oakley et al., 2015). As noted previously, stereotypic motor disorder may be a presenting symptom of ASD, which should be considered in the assessment and evaluation of repetitive movements and behaviors (APA, 2013). Several other disorders may co-occur with stereotypic disorder. A recent study that extended the period of follow-up through adolescence assessed the course of movement abnormalities with stereotypic movement disorder as well as documented comorbidities. This study found that stereotypic movement disorder was associated with high rates of comorbid ADHD (63 percent), obsessive-compulsive symptoms (35 percent), tics/Tourette syndrome (22 percent), and anxiety (71 percent) (Oakley et al.). Moreover, stereotypic movement disorder may occur as a primary diagnosis or a secondary diagnosis to another disorder. For example, stereotypies are a common manifestation of a variety of neurogenetic disorders, such as Lesch-Nyhan syndrome, Rett syndrome, fragile X syndrome, Cornelia de Lange syndrome, and Smith-Magenis syndrome (APA, 2013).

Youth with tic disorders frequently experience co-occurring obsessive-compulsive disorder and ADHD (APA, 2013). One study of 3,500 participants from a worldwide sample revealed that 88 percent of all individuals with Tourette disorder have at least one other co-occurring disorder. Of that 88 percent, 60 percent reported having comorbid ADHD and 59 percent reported having obsessive-compulsive behaviors. Males were significantly more likely to report comorbid symptoms than females (Robertson, Eapen, & Cavanna, 2009). Individuals with tic disorders can also have other movement disorders, as well as depressive, bipolar, or substance-use disorders (APA).

The vulnerability toward developing co-occurring disorders changes as individuals pass through the age of risk for various co-occurring conditions. Pre-pubertal children with tic disorders are more likely to experience ADHD, obsessive-compulsive disorder, and separation anxiety disorder than are teenagers and adults, who are more likely to experience the new onset of major depressive disorder, substance use disorder, or bipolar disorder (APA, 2013).

Any assessment of a child or adolescent that reveals the presence of tics should prompt assessment for co-occurring mental health disorders. Given the frequent comorbidity of tic disorders with other psychiatric conditions, incorporating measures for comorbid conditions into the assessment of youth is frequently warranted (Murphy et al., 2013).

#### **Treatments**

The treatments for tic disorders are those with the most evidence at this time. Comprehensive behavioral intervention for tics and habit reversal therapy (HRT) are the only treatments for tic disorders researched sufficiently to warrant the designation of evidence-based treatment. Pharmacotherapy may also be appropriate for youth with tic disorders when the disorder causes impairment in the youth's quality of life and when there are co-occurring psychiatric conditions that will respond to medication. Table 4 outlines the treatments available for motor disorders.

Table 4
Summary of Treatments for Motor Disorders

What Works				
Habit reversal therapy (HRT) for tic disorder	Treatment increases awareness to the feelings and context associated with the urge to tic and implements a competing and inconspicuous habit in place of the tic.			
Comprehensive behavioral intervention for tics (C-BIT)	Combines habit reversal and other approaches like education, awareness via self-monitoring, relaxation techniques, and sometimes situational changes.			
What Seems to Work				
Exposure with response prevention (ERP)	Consists of repeated, prolonged exposures to stimuli that elicit discomfort and instructions to refrain from any behavior that serves to reduce discomfort.			
Pharmacotherapy	Medications may be considered for moderate to severe tics causing severe impairment in quality of life or when medication responsive psychiatric comorbidities are present that target both tic symptoms and comorbid condition.			
Massed negative practice	Treatment involves children's over-rehearsal of target tic in high-risk situations.			
What Does Not Work				
Deep brain stimulation	Surgical intervention; not recommended.			
Repetitive transcranial magnetic stimulation (rTMS)	Safety in youth has not been established; not recommended.			
Plasma exchange; Intravenous immunoglobulin (IVIG) treatment	Blood transfusions alter levels of plasma or immunoglobulin. While several of these treatments have been shown to be promising, they are not empirically supported and not recommended.			
Dietary supplements (magnesium and vitamin B6); Special diets	Supplements may have the potential to negatively interact with other pharmacological agents. Not recommended until safety in children is established.			

Sources: Murphy et al., 2013; Centers for Disease Control [CDC], 2012; Piacentini et al., 2010; Cook & Blacher, 2007; Himle et al., 2006; Woods, Flessner, & Conelea, 2008; Woods, Piacentini, & Himle, 2007; National Institutes of Mental Health [NIMH], 2000.

## Habit Reversal Therapy (HRT)

Habit reversal therapy (HRT) is the most well-studied and most effective treatment for youth with motor disorders (Tucker, Conelea, & Woods, 2012; Cook & Blacher, 2007; Himle et al., 2006). Though treatments may vary slightly, HRT includes three main components, as cited by Woods, Flessner, & Conelea, 2008:

- 1. Awareness training;
- 2. Competing response training; and
- 3. Social support.

Awareness training involves first teaching youth to become aware of instances of the habit, then teaching awareness of the associated environment and internal sensations, such as muscle tension and urges (van de Griendta et al., 2013). Once the youth is able to identify feelings and situations likely to elicit the habit, competing response training begins. A competing response is a behavior that is incompatible with the habit that is performed in the presence of the feelings or situations that elicit the habit or in the presence of the habit itself. Competing responses must meet the following criteria:

- Must be physically incompatible with the habit (e.g., holding the arm close to the body to compete with an arm movement tic);
- Must be socially inconspicuous; and
- Must be held for one minute or until the urge to engage in the habit dissipates.

Supportive individuals are recruited to provide gentle reminders when the youth is engaging in the habit and praise when the competing response is implemented correctly (Woods, Flessner, & Conelea, 2008). The social support component runs concurrently with other phases of treatment.

Follow-up studies of HRT in youth with tic disorders show success at six months to two years, and secondary symptoms (including anxiety, disruptive behavior, family strain and social functioning) improved (van de Griendta et al., 2013).

Other treatments for stereotypic motor disorder have shown promise. One study assessed the effectiveness of a behavioral treatment that combines modified HRT and a treatment called "differential reinforcement of other behavior" in reducing the occurrence of stereotypic movement disorder in non-autistic children (Miller et al., 2006). The study found that this combination provides a potentially valuable treatment option, but success requires a motivated patient, multiple training sessions, and an experienced therapist (Miller et al.). Further study with a larger number of patients with longer follow-up is needed. Another study was conducted to evaluate the efficacy of an instructional DVD as a home-based, parent-administered behavioral therapy for reducing stereotypies in children with primary complex motor stereotypes (Specht et al., 2017). While the study has limitations, results suggest that parent-administered therapy effectively reduces primary motor stereotypy severity.

#### Comprehensive Behavioral Intervention for Tics (C-BIT)

Comprehensive behavioral intervention for tics (C-BIT) combines habit reversal and awareness of tics through techniques like self-monitoring, along with education about tics and relaxation techniques (Centers for Disease Control [CDC], 2012; Piacentini et al., 2010). A therapist works with the child and his or her family to understand the types of tics and situations in which the tics occur (CDC). Where HRT combines tic awareness and competing-response training, C-BIT includes relaxation training and functional intervention. C-BIT helps the patient identify situations in which tics occur and develop strategies to overcome the tic (Piacentini et al.).

In one C-BIT trial, 126 youth with Tourette disorder were randomized to an 8-session, 10-week HRT-based intervention. For those youth, over 52 percent responded compared to 18 percent in the control group. Moreover, the reduction in tic symptom severity was 51 percent. The C-BIT intervention included sessions with focus on the functional assessment of tics. These sessions aimed to help parents to identify factors that sustained or exacerbated tics (Murphy et al., 2013).

## Exposure with Response Prevention (ERP)

Exposure with response prevention (ERP) is a treatment in which a youth is asked to suppress his or her tics for prolonged periods of time. The theory behind ERP is that the youth is exposed to the premonitory sensations (premonitory urges or "sensory tics") associated with tic expression and begins to adjust to them, thus causing the urge to produce a tic to diminish. Two single-case studies found the treatment to be effective, although booster sessions were recommended to maintain treatment effects. Two studies were carried out that tested for the rebound effect post-ERP treatment, whereby tic frequency increases after an ERP session. Neither study demonstrated a rebound effect, thus supporting the theory that youth learn through ERP that the premonitory sensation can be tolerated to some extent, and that there is no need to release tension afterwards. ERP is currently considered to be effective; however, long-term effects need to be determined (Frank & Cavanna, 2013).

## Pharmacotherapy

According to the American Academy of Child and Adolescent Psychiatry, medications for chronic tic disorders should be considered for moderate to severe tics that cause severe impairment in quality of life, or when comorbid conditions are present and the medication targets both tic symptoms and comorbid conditions (Murphy et al., 2013). A meta-analysis to determine the efficacy of antipsychotics and alpha-2 agonists (a class of drug that selectively stimulates alpha adrenergic receptors) demonstrated that both were effective in treating tics. However, the study's findings suggest that alpha-2 agonists may have minimal benefit in tic patients who do not have co-occurring ADHD (*Clinical Trials Week*, 2014).

Treatment of ADHD in the context of tic disorders can, at times, be challenging because of concerns of worsening tic severity. Recent studies have demonstrated that tics are not universally increased by stimulant medication in children with ADHD (Murphy et al., 2013). For example, several investigators have shown that the potential impact of stimulants on the development of tics is minimal or of short duration and that a definite causal effect is present in very few children. For youth with co-occurring tic disorders and ADHD, results showed that the

stimulants studied were associated with significant improvement in ADHD symptoms (Robertson, 2017). However, it should be noted that the FDA package insert for stimulants does list tics as a contraindication (Murphy et al). For youth with disabling obsessive-compulsive symptoms, pharmacologic treatments, along with behavioral treatments, may be helpful. Selective serotonin reuptake inhibitors (SSRIs) and clomipramine has been demonstrated to be beneficial in several studies (Murphy et al.).

## Massed Negative Practice

Massed negative practice is based on the premise that over-rehearsal of the tic by youth can lead to its disappearance. One study assessing the effectiveness of massed negative practice with HRT showed that the youth receiving massed negative practice showed a 33 percent tic reduction following the first day, and an average tic reduction of 25 percent at four-week follow-up (Tucker, Conelea, & Woods, 2012). In comparison, HRT was associated with an 84 percent tic reduction following the first day of treatment, and gains appeared to be maintained through an 18-month follow-up. However, this study did not include an inactive control group, suggesting that this treatment may be a minimally effective treatment for tics, albeit much less effective (Tucker, Conelea, & Woods).

## Treatments with Inadequate Support

Deep brain stimulation, repetitive transcranial magnetic stimulation (rTMS), and special diets lack empirical support for the treatment of tic disorders and are not recommended (Murphy et al., 2013). Deep brain stimulation is a surgical treatment approach that may hold benefit for adults; however, few cases have been reported of youth receiving it and guidelines have advised that this procedure should not be conducted in individuals less than 25 years of age outside of a research setting. A study examining repetitive transcranial magnetic stimulation (rTMS) in youth with Tourette disorder has been conducted with no reported adverse outcomes. However, very few youth have received rTMS and this treatment option should be considered preliminary until larger blinded studies have resolved issues regarding its safety (Murphy et al.). Research has also shown a lack of evidence to support treatment using either plasma exchange or intravenous immunoglobulin (IVIG).

One study found that approximately 60 percent of patients with Tourette disorder use complementary and alternative medicines, and about 80 percent initiate such therapies without informing their doctor (Lyon et al., 2010). Although many patients with tic disorders do use complementary and alternative medical therapies, support for this practice is not currently at the evidence-based level. Both the NIMH and the Tourette Syndrome Association (TSA) had previously advised that some therapies, such as high-dose vitamin B6 or St. John's wort, have the potential for interactions with medications and are not recommended until studied appropriately in children (NIMH, 2000). A clinical trial was undertaken to study the effectiveness and safety of magnesium and vitamin B6. The results of a clinical trial published in 2009 shows that treatment with vitamin B6 and magnesium could be helpful in controlling Tourette syndrome and side effects associated with it. However, the researchers state that more studies are required before conclusively establishing the benefits of magnesium for Tourette syndrome (Garcia-Lopez et al., 2009).

#### **Cultural Considerations**

Research suggests that motor disorders are prevalent across cultures (Woods, Flessner, & Conelea, 2008). The understanding of the disorder varies significantly from culture to culture. For example, in Costa Rica, tic symptoms are not considered a problem and are not usually mentioned to physicians (Mathews, 2001). Many families consider the tics to be a voluntary bad habit and health care professionals, when consulted, may concur (Mathews).

Tourette disorder is less prevalent in African Americans and Hispanic Americans (APA, 2013; CDC, 2012; Robertson et al., 2009). However, Tourette disorder is very rare in sub-Saharan African people, which may explain its rarity in African Americans (Cohen, Leckman, & Bloch, 2013; Robertson et al.).

A Tourette disorder study in the United Kingdom (U.K.) and United Arab Emirates showed similar core symptoms, yet there were more behavioral symptoms in the U.K. sample (Eapen & Robertson, 2008). These results strengthen the case for a biological and genetic basis for Tourette disorder, but they imply that Tourette disorder may have phenotypes or additional treatment paths (Eapen & Robertson).

Tourette disorder is less prevalent in China than in the rest of the world, but the discrepancy may be due to a stricter diagnostic system (Robertson et al., 2009). Some studies suggest that slightly different symptoms present in different nations, but that is unproven. Whether this variation truly exists is debated (Robertson et al.).

#### **Overview for Families**

Unless otherwise cited, information in this section is taken from the DSM-5 (APA, 2013).

Motor disorders encompass a variety of disorders, many of which have symptoms of seemingly involuntary, repetitive motion. Developmental coordination disorder, stereotypic movement disorder, and the tic disorders, including Tourette syndrome, are all classified as motor disorders. The main features of these motor disorders are listed below:

#### Developmental Coordination Disorder

- Onset in early development
- Motor skills are developed and carried out substantially below expectations based on age and education
- Signs include clumsiness and slow/inaccurate motor skills

#### Stereotypic Movement Disorder

- Onset in early development
- Repetitive, driven, and purposeless motor behavior
- Signs include shaking, rocking, and hitting self

#### Tic Disorders

#### Tourette disorder

- Onset before age 18
- Multiple motor tics and one or more vocal tics, all of which have been present for at least one year since the first tic onset
- Frequency may change over time; tics do not necessarily have to happen concurrently

#### Persistent (chronic) motor or vocal tic disorder

- Onset before age 18
- Single or multiple motor or vocal tics, but not both, that have been present for at least one year since the first tic onset
- Frequency of tics may change over time

#### Provisional tic disorder

- Onset before age 18
- Single or multiple motor and/or vocal tics
- Present multiple times daily or almost daily
- Tics present for more than four weeks and less than one year

Males are more likely than females to develop motor disorders. Onset of tics typically occurs between the ages of four and six, with severity peaking between the ages of 10 and 12. Families should seek a comprehensive evaluation with a qualified service provider when symptoms of a motor disorder become prevalent (American Academy of Child & Adolescent Psychiatry [AACAP], 2012). Families may need to work with clinicians and the child's teachers to change situations in the child's day to help reduce the urge to tic (Piacentini, 2010).

## **Resources and Organizations**

## American Academy of Child, & Adolescent Psychiatry (AACAP)

http://www.aacap.org/

#### **American Academy of Family Physicians**

Understanding Tics and Tourette's Syndrome

https://www.aafp.org/afp/1999/0415/p2274.html

#### **American Psychiatric Association (APA)**

https://www.psychiatry.org/

#### **American Psychological Association (APA)**

http://www.apa.org/

#### **Association for Neurologically Impaired Children (AFNIC)**

http://www.afniconline.org

#### **Jim Eisenreich Foundation (for children with Tourette Syndrome)**

http://www.tourettes.org

#### **National Alliance for the Mentally III (NAMI)**

https://www.nami.org/

#### **Tourette Syndrome Association, Inc.**

https://www.tourette.org/

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# Schizophrenia

Introduction

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#### Introduction

Schizophrenia is a pervasive, devastating, neuropsychiatric disorder associated with extreme deficits in cognition, behavior, and social functioning (McClellan & Werry, 2001). Estimates indicate that schizophrenia occurs in one percent of populations worldwide and in all known cultural and ethnic groups (McDonell & McClellan, 2007). Onset of schizophrenia typically occurs between age 16 and 30; the rate of onset increases during adolescence, peaking at age 30 (Mueser & McGurk, 2004; McClellan & Werry). Schizophrenia in youth is rare, only accounting for one percent of individuals with schizophrenia. Therefore, most information used to diagnose and treat this group of people has been attained from studies with adult participants (Brown et al., 2008; Kumra, 2008).

Onset before age 18 is categorized as early-onset schizophrenia (EOS) whereas onset before age 13 is categorized as childhood-onset schizophrenia (COS) (McClellan, Stock & American Academy of Child and Adolescent Psychiatry [AACAP] Committee on Quality Issues [CQI], 2013). This very early onset is exceedingly rare and much more severe than EOS. Although earlier onset is associated with poorer outcomes, earlier treatment of schizophrenia may reduce the likelihood of the child's functional decline and long-term impairment (NAMI, 2010). For the purposes of this section of the *Collection*, the terms schizophrenia and EOS will be used interchangeably.

Males are 1.4 times more likely to be diagnosed than females and most youth with EOS maintain the diagnosis over time (NAMI, 2010; McClellan, Stock & AACAP CQI, 2013; McClellan & Werry, 2001; Asarnow, Tompson & McGrath, 2004). Studies have shown that the most common criteria in EOS are hallucinations, formal thought disorder, and flattened affect, (i.e., lack of emotions or emotional response). Systematic delusions and catatonic symptoms (i.e., motor immobility and stupor) are less common (McClellan & Werry; Pavuluri, Herbener & Sweeney, 2004). Although these criteria are consistently found in EOS, it is important to note that EOS is a phasic disorder with much individual variability (Werry, McClellan & Chard, 1991; Asarnow & Tompson, 1999).

## Recent Changes from the DSM-IV to the DSM-5

In 2013, the American Psychiatric Association released the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*). Several key changes were made to the schizophrenia category. The *DSM-5* raises the symptom threshold, requiring that an individual exhibit at least two of the specified symptoms (the threshold was previously one in the *DSM-IV*) (American Psychiatric Association [APA], 2013a). Additionally, the diagnostic criteria no longer identify schizophrenia subtypes. Subtypes were previously defined by the predominant symptom at the time of evaluation but were not always helpful to clinicians because patients' symptoms often changed from one subtype to another. Thus, patients could have overlapping subtype symptoms, which blurred distinctions and decreased their validity (APA). Some of the former subtypes are now specifiers to help provide further detail in diagnosis. For example, catatonia is now used as a specifier for schizophrenia.

According to the AACAP Practice Parameters, the diagnosis of EOS is made using the same *DSM-5* criteria as those for adults. Evidence shows that EOS and adult-onset schizophrenia are most likely the same disorder (McClellan, Stock & AACAP CQI, 2013).

The *DSM-5* is a manual for assessment and diagnosis of mental health disorders and does not include information for treatment of any disorder. In the future, more evidence supporting treatments of disorders with *DSM-5* classifications will be available as clinical studies using *DSM-5* criteria are conducted. As a result, the *Collection* will reference studies that utilize *DSM-IV* diagnostic criteria to explain symptoms and treatments.

#### **Causes and Risk Factors**

It is likely that genetic, behavioral, and environmental factors influence the development of EOS (Kodish & McClellan, 2008). Developmental and/or behavioral abnormalities are common with EOS; some reports indicate incidence as high as 90 percent (McClellan & Werry, 2001; McDonell & McClellan, 2007). Environmental factors can intensify genetic or neurodevelopmental deficiencies; thus, findings point to a combination of and interaction between genetic and environmental influences (U.S. Department of Health and Human Services, 1999). Environmental factors associated with schizophrenia include maternal malnutrition, infections during critical periods of fetal development, fetal hypoxia (a lack of oxygen to the brain), and other birth and obstetric complications (Carpenter, 2004). Prenatal malnutrition may also increase the likelihood of schizophrenia, including a lack of folate in the mother's diet (Susser et al., 1996; Kirkbride et al., 2012).

Research indicates that early central nervous system lesions have been shown to affect the normal maturational processes of the brain in youth with schizophrenia (McClellan & Werry, 2001). The initial findings of a National Institute of Mental Health (NIMH) study of EOS showed that youth who had psychotic episodes before puberty demonstrated evidence of progressively abnormal brain development (NIMH, 2001). Major changes occur in the brain during puberty, which could trigger symptoms of schizophrenia (NIMH, 2007). This study revealed that ventricles enlarged abnormally in youth ages 14 to 18 with EOS, suggesting a shrinking of brain tissue volume. This shrinking is significant because losses in the rear of the brain are influenced primarily by environmental factors and suggest that a non-genetic cause may play a role in the initial progression of the disorder. The brain loss pattern in youth is consistent with that seen in adults with schizophrenia.

The literature shows no evidence that psychosocial factors cause schizophrenia (McClellan, Stock & AACAP CQI, 2013). Evidence does suggest that the onset, course, and severity of schizophrenia are due to the interaction between environmental and biological risk factors. Psychosocial factors play a part by influencing the onset, episode intensity, and relapse rate. Earlier onset age has been associated with more severe impairments (Kodish & McClellan, 2008). EOS is linked to poorer functional outcomes and increased negative symptoms in adulthood (McClellan & Werry, 2001).

There are strong correlations with the incidence of schizophrenia and other seemingly unrelated symptoms. People who are left-handed or ambidextrous make up a significant portion of those with schizophrenia, and, although being left-handed does not cause schizophrenia, there is a relationship between the two factors (Webb et al., 2013). The same link without causation is true for children who exhibit motor difficulties. While these connections exist, they may be primarily anecdotal and should not be cause for concern alone. The presence of these attributes does not ensure that there is a definitive correlation (*New York Times*, 2013).

Studies have shown that schizophrenia is highly influenced by genetics. Compared to the general population, the risk of being diagnosed with schizophrenia is five times higher for second-degree relatives of persons who have schizophrenia, ten- to fifteen-fold higher for first-degree family members (including dizygotic (fraternal) twins), and forty to fifty times higher for monozygotic (identical) twins or when both parents have schizophrenia (Carpenter, 2004).

#### **Prevalence**

Figure 1 describes the prevalence of EOS.

#### Figure 1

## Prevalence of Early-Onset Schizophrenia (EOS)

#### Prevalence of EOS: 0.1%

Approximately 1 in 100 people are diagnosed with schizophrenia (1%). An estimated 1 in 100 of those with schizophrenia developed it in childhood (0.1%).

#### Ratio of males to females: 1.4:1

Males are 1.4 times as likely as females to develop schizophrenia. Boys are more likely to develop EOS between age 15 and 24, whereas women are more likely to develop schizophrenia between 25 and 34. The earlier a girl starts menstruating, the more protection she has against developing schizophrenia.

#### Heredity

Genetics may affect prevalence as well, as one is 5 to 20 times more likely to develop schizophrenia than the general population if one is a first-degree relative of affected persons.

Sources: NAMI, 2010; McCLellan, Stock & AACAP CQI, 2013; New York Times, 2013; McClellan & Werry, 2001).

#### **Assessment**

Proper assessment of EOS in youth is essential in early diagnosis, intervention, and treatment. Although no information on early intervention is available in the EOS literature, research shows that the duration of untreated psychosis predicts poorer outcomes in adults with schizophrenia (Harrigan, McGorry & Hrstev, 2003). Unfortunately, EOS is often misdiagnosed because of its rarity and because its symptoms are similar to other mood disorders (McClellan & Werry, 2001). To prevent misdiagnosis and increase the chance of a better prognosis in youth, a complete, multi-informant, multi-method assessment is key (McDonell & McClellan, 2007). The AACAP practice parameter recommends that the assessment also incorporate an understanding of the youth's developmental, social, educational, and psychological needs (McClellan & Werry; McClellan, Stock & AACAP CQI, 2013).

The *DSM-5* outlines several related symptoms that may assist in a schizophrenia diagnosis (APA, 2013b). Along with a lack of awareness of his or her illness, a youth may display:

- Inappropriate affect, such as laughing without the appropriate stimulus
- Disturbed sleep pattern
- Dysphoric mood that might mimic depression, anxiety, or anger
- Lack of interest in food or food refusal
- Depersonalization, derealization, and/or somatic concerns, all of which may reach delusional levels
- Anxiety and phobias

- Cognitive deficits, including slower processing speed and decreased:
  - Declarative memory
  - Working memory
  - Language function
  - Other executive function
- Deficits in the ability to infer others' intentions
- Abnormalities in the following:
  - Sensory processing
  - Inhibitory capacity
  - Attention
- Hostility or aggression

A comprehensive diagnostic assessment should include interviews with the youth and his or her family, a review of past records and other pertinent information, and a detailed evaluation of the psychotic symptoms (McClellan & Werry, 2001). Symptom presentation, course of illness, confounding factors, family psychiatric history, and a mental status examination are important issues that should be addressed during the assessment. During the initial assessment period, the clinician should choose both broadband (general screening tools) and narrowband (specific to disorder) measures in order to eliminate or confirm other possible diagnoses or comorbid disorders.

One of the first steps in assessing for EOS is an examination by a primary care provider to rule out a medical reason for the youth's change from normal behavior. Many medical conditions, such as delirium, seizure disorders, central nervous system lesions, neurodegenerative disorders, and developmental disorders, can cause organic psychosis (McClellan & Werry, 2001). Psychotic symptoms brought on by substance abuse should also be ruled out. Other conditions that should be ruled out prior to a diagnosis of schizophrenia include psychotic mood disorders, behavioral/emotional disorders, schizoaffective disorder, autism spectrum disorder, obsessive-compulsive disorder, and delusional disorders.

McClellan, Stock, and the AACAP CQI (2013) published a report that included recommendations for the appropriate diagnosis of schizophrenia in children and adolescents. The following are their recommendations for diagnosing youth with EOS.

- 1. Psychiatric assessments for children and adolescents should include screening questions for psychosis.
- 2. The diagnosis of schizophrenia in children and adolescents should follow DSM-5 criteria.
- 3. Youth with suspected schizophrenia should be carefully evaluated for other pertinent clinical conditions and/or associated problems, including suicidality, comorbid disorders, substance abuse, developmental disabilities, psychosocial stressors, and medical problems (McClellan, Stock & AACAP CQI).

Suggested assessment tools for schizophrenia are outlined in Table 1.

Table 1
Suggested Assessment Tools

Measure Type	Name of Measure	Who Completes	Data Generated
Clinical interview	Schedule for Affective Disorders and Schizophrenia for School-Age Youth present and lifetime (K-SADS-P/L)	Clinician with youth and parent	Diagnosis
Clinical interview	Structured Clinical Interview for <i>DSM-IV</i> , Childhood Diagnoses (KID-SCID)	Clinician with youth and parent	Diagnosis
Symptom rating scale	Scale for the Assessment of Positive Symptoms (SAPS)	Clinician with youth	Symptom ratings
Symptom rating scale	Scale for the Assessment of Negative Symptoms (SANS)	Clinician with youth	Symptom ratings
Symptom rating scale	Positive and Negative Syndrome Scale	Clinician with youth	Symptom ratings
Behavior checklist	Youth Self-Report (YSR)	Youth	Syndrome scale scores; competence scores
Behavior checklist	Child Behavior Checklist (CBCL)	Parent	Syndrome scale scores; competence scores

Source: McDonell & McClellan, 2007.

In addition, clinicians must acknowledge developmental, cultural, and intellectual factors that may influence assessment and diagnosis. This will allow the clinician to interpret clinical data correctly and to differentiate between appropriate and inappropriate behavior. It is also imperative that the clinician assesses not only for symptoms, but also for functional impairment and the degree to which the youth functions at home, school, and in play.

Personality and projective tests are not indicated as a method of diagnosing schizophrenia in youth; research indicates no demonstrated ability to increase the diagnostic accuracy of EOS when using tools such as the Rorschach (McDonell & McClellan, 2007).

# Diagnostic Criteria

In order to receive a diagnosis of schizophrenia, there must be ongoing signs for six months. Two or more of symptoms below must be present for at least one month, one of which must be (1), (2), or (3).

- 1. Delusions
- 2. Hallucinations
- 3. Disorganized speech (indicating disorganized thinking)
- 4. Grossly disorganized or abnormal motor behavior (including catatonia)
- 5. Negative symptoms such as:
  - Diminished emotional expression
  - Avolition (lack of motivation to complete goals)
  - Alogia (diminished speech, even when pressured to engage)
  - Anhedonia (inability to experience pleasure from positive stimuli)
  - Asociality (lack of interest in social interactions)

Clinicians must rule out schizoaffective disorder and depressive or bipolar disorder with psychotic episodes, as well as a drug or medicine causing the symptoms (APA, 2013b). Finally, if a child has a history of autism spectrum disorder or a communication disorder, the child must experience prominent delusions or hallucinations for at least one month (APA). If the delusions, hallucinations, and/or disorganized speech do not persist for most of a month due to treatment, a schizophrenia diagnosis may still appropriate if the symptoms would have persisted without the treatment (APA). Additionally, the child's functioning level must be significantly below the functional level prior to onset (APA). Areas of functioning include academics, occupational functioning, or personal relationships.

Table 2 outlines associated features of schizophrenia that may persist during remission of other symptoms.

Table 2
Associated Features of Schizophrenia

Feature	Explanation
Inappropriate affect	For instance, laughing without appropriate stimulus or at inappropriate times
Dysphoric mood	Exhibiting signs of depression, anxiety, or anger
Disturbed sleep pattern	Daytime sleeping and nighttime activity
Disturbed eating	Lack of interest in or refusal of food
Cognitive defects	Vocational and functional impairments in declarative memory, working memory, language function, other executive functions; slower processing speed
Social cognition defects	Difficulty inferring the intentions of others; interpreting irrelevant stimuli as meaningful, leading to the generation of explanatory delusions
Anosognosia	Lack of insight of schizophrenia symptoms and/or illness; typically a symptom rather than a coping strategy

Source: APA, 2013b.

Symptoms of schizophrenia can be divided into three groups: positive, negative, and cognitive symptoms (NIMH, 2009). Positive symptoms are defined as psychotic behaviors not seen in healthy individuals. Individuals with positive symptoms will have lost their hold on reality (NIMH). Negative symptoms, which are more subtle, are disruptions in normal emotions and behaviors (NIMH). Finally, cognitive symptoms, which are similar to negative symptoms in their subtlety, are disruptions in the functionality of the brain in everyday processes (NIMH). The three categories are described in Table 3.

The most common criteria for EOS are vivid hallucinations (this is unique to EOS as compared to adult schizophrenia), formal thought disorder, and flattened affect. Systematic delusions and catatonic symptoms are less common (McClellan & Werry, 2001; Pavuluri, Herbener & Sweeney, 2004). The variation of language and cognition in children may affect the symptoms present (McClellan Stock & AACAP CQI, 2013). Cognitive delays often co-occur with EOS, including memory, executive functioning, attention deficits, and global impairments (McClellan, Stock & AACAP CQI). At onset of schizophrenia, children often show cognitive decline (McClellan, Stock & AACAP CQI).

Prior to diagnosis, children often exhibit social withdrawal, disruptive behavior disorders, difficulty in school, and speech and language problems (McClellan, Stock & AACAP CQI, 2013). Signs of schizophrenia often present slowly over time, so parents often have difficulty recognizing psychotic symptoms in children with language delays and social withdrawal (McClellan, Stock & AACAP CQI). Parents should look for unusual, suspicious, or paranoid thoughts along with language and social decline (McClellan, Stock & AACAP CQI).

In a recent study, over 50 percent of children thought to have schizophrenia were eliminated from participation because they had another mental health issue with symptoms similar to schizophrenia (Rapoport, 2013). Because misdiagnosis is a major issue in the assessment and diagnosis of EOS, clinicians should take care to differentiate true psychotic symptoms from overactive imaginations, idiosyncratic thinking, and perceptions caused by developmental delays and/or exposure to traumatic events. Symptoms must represent a marked change in mental status or level of functioning (McClellan & Werry, 2001).

Since EOS is a phasic disorder, individual variability must be considered when working with youth. Differences in clinical presentation of EOS across the phases must be taken into account during assessment and diagnosis. These phases and corresponding descriptions are listed below (Centre for Addiction and Mental Health [CAMH], n.d.).

<u>Prodromal Phase:</u> Prior to developing overt psychotic symptoms, affected youth will experience some period of deteriorating function, which may include social isolation, idiosyncratic or bizarre preoccupations, unusual behaviors, academic problems, and/or deteriorating self-care skills. However, while the presence of these problems should raise concerns, psychotic symptoms must be present before a diagnosis of schizophrenia can be made.

Table 3
Positive, Negative, and Cognitive Symptoms of Schizophrenia

Types described below. May also involve thought withdrawal or insertion, or the belief that one is controlled by an outside force.
Belief that a person or group will harm, harass, or otherwise bother the individual; most common type of delusion
Belief that certain gestures, comments, and environmental cues are directed at the individual
Individual believes he/she has exceptional abilities, wealth, or fame
Individual falsely believes someone is in love with him/her
Belief that a major catastrophe will occur
Focus on preoccupations on health and organ function
Belief that one is a religious figure
Auditory, visual, tactile and/or olfactory (smell) experiences which occur without an external stimulus
Loosening of associations; tangential or incoherent speech – adequate to impair communication
Behavior that ranges from silliness to erratic tension; difficulty in sustaining goal-oriented behavior
Lack of response to environment, motor immobility, mutism, posturing or stereotyped behavior, excessive motor behavior, echolalia (unconventional verbal behaviors), or echopraxia (imitation of movements of others)
Reductions in facial expression, eye contact, hand movements, and speech intonation
Difficulty initiating and maintaining motivation to complete tasks
Diminished amount and quality of speech
Less able to experience pleasure from positive stimuli or forgetting previous pleasures experienced
Limited facial affective expression, eye contact, and body language
Inability to learn/understand information and then use it to make decisions
Inability to sustain attention over long periods of time
Inability to effectively utilize information immediately after learning it

Sources: McDonell & McClellan, 2007; APA, 2013b; NIMH, 2009.

<u>Active Phase:</u> During schizophrenia's active phase, those affected may experience delusions, hallucinations, marked distortions in thinking, and disturbances in behavior and feelings. This phase most often appears after a prodromal period. On occasion, these symptoms can appear suddenly.

Residual Phase: After an active phase, those affected may be listless, have trouble concentrating, and be withdrawn. The symptoms in this phase are similar to those outlined under the prodromal phase. If there have been no symptoms before the first episode, few or no symptoms may be experienced afterward. During their lifetimes, people with schizophrenia may become actively ill only once or twice or may have many more episodes. Unfortunately, residual symptoms may increase and ability to function may decrease after each active phase. It is important to try to avoid relapses by following the prescribed treatment. Currently it is difficult to predict at the onset how fully a person will recover.

While schizophrenia symptoms must be present for one month, the disorder cannot be further clarified by a specifier until certain symptoms persist for at least one year (APA, 2013b). In such cases, longitudinal assessment is essential for confirming a tentative EOS diagnosis. Clinicians should rule out other disorders (e.g., schizoaffective disorder, mood disorders with psychotic features) before making a diagnosis of EOS.

## Comorbidity

Youth suffering from EOS also have high rates of comorbid conditions (McDonell & McClellan, 2007). These disorders include:

- Depression
- Anxiety
- Externalizing disorders, such as:
  - Attention-deficit/hyperactivity disorder (ADHD),
  - Conduct disorder, and/or
  - Oppositional defiant disorder (McClellan, Breiger, McCurry & Hlastla, 2003)

In addition, developmental delays and cognitive difficulties are found at a high rate in youth with EOS. Autism spectrum disorder is also a common first diagnosis and/or comorbid disorder (McDonell & McClellan).

In adolescents with EOS, comorbid substance abuse is also a major issue (Kumra, Thaden & Kranzler, 2005). Although no research has been conducted with youth diagnosed with schizophrenia and comorbid substance abuse, research in adults has shown that nicotine use is the most common form of substance abuse, and that over half of adults with schizophrenia use tobacco products regularly (NIMH, 2007; APA, 2013b).

At least one study considered the frequency of comorbid disorders in children with EOS. The rates are outlined in Table 4.

Table 4

Prevalence of Comorbid Disorders in Youth with EOS

Disorder	Comorbidity Prevalence Rate	
ADHD	84%	
Oppositional defiant disorder	43%	
Depression	30%	
Separation anxiety disorder	25%	

Source: Ross, Heinlein & Tregellas, 2006.

#### Suicide Risk

The *DSM-5* warns of the salient risk suicide poses for those with schizophrenia (APA, 2013b). Between five and six percent of individuals with schizophrenia die of suicide, and approximately 20 percent attempt it (APA). Even more of these individuals experience suicidal ideation (thoughts of suicide) (APA). According to the *DSM-5*, suicide risk is high throughout the life of both males and females. However, it may be highest in young males who also use or abuse drugs and similar substances. The likelihood of suicide is highest when a youth is in a depressive state or is experiencing depression-like symptoms, after a psychotic episode, or after being discharged from the hospital (APA). Monitoring youth with EOS for suicide risk is extremely important. A review of suicide assessment tools is provided in the *Collection*'s "Youth Suicide" section.

#### **Treatments**

The AACAP Practice Parameter for treatment of EOS recommends a comprehensive, multimodal combination of both psychopharmacology and psychosocial therapies (McClellan, Stock & AACAP CQI, 2013). Antipsychotics are usually prescribed immediately following a diagnosis of schizophrenia. Typically, antipsychotics and therapy are continuous throughout a child's or adolescent's life, as relapses are linked with the discontinuation of either forms of treatment (McClellan, Stock & AACAP CQI). Once an individual relapses for any reason, it becomes harder to maintain a baseline. Furthermore, after each subsequent relapse, it becomes more difficult to return to normal health and functioning, and the likelihood of more relapses and staying unhealthy increases. This decline can have irreversible effects; therefore, vigilance is essential (Emsley, Chiliza, Asmal, & Harvey, 2013).

The AACAP also advises that treatment should acknowledge several factors, including treatment setting, the age of the youth, and the family environment. The focus of therapy, as set out by the AACAP, is to alleviate symptoms, reduce long-term mortality, and prevent relapse, while maintaining youth in their homes and communities.

Currently, there are no pharmacological or psychosocial therapies with enough evidence in youth samples to meet the highest standard for evidence-based treatments (McClellan, Stock & AACAP CQI, 2013). Thus, research on treatment of EOS is recent and sparse.

Table 5 summarizes treatments for EOS.

Table 5
Summary of Treatments for Early-Onset Schizophrenia

What Works			
There are no evidence-based practices at this time.			
What Seems to Work			
Psychopharmacological treatment with second-generation (atypical) antipsychotics	Risperidone Aripiprazole Quetiapine Paliperidone Olanzapine		
Psychopharmacological treatment with traditional neuroleptics/first generation antipsychotics	Molindone Haloperidol		
Family psychoeducation and support	Helps to improve family functioning, problem solving and communication skills, and decrease relapse rates.		
Cognitive behavioral therapy (CBT)	Includes social skills training, problem-solving strategies, and self-help skills.		
Cognitive remediation	Pointed tasks to help improve specific deficiencies in cognitive, emotional, or social aspects of a patient's life.		
Not Adequately Tested			
Electroconvulsive therapy (ECT)	Small electric currents are passed through the brain, intentionally triggering a brief seizure to reverse symptoms of certain mental illnesses. Unproven as effective in youth. Should only be used as a last effort after all risks are weighted against possible benefits.		
What Does Not Work			
Psychodynamic therapies	Talk therapies that focus on a client's self-awareness and understanding of the influence of the past on present behavior. These therapies are considered to be potentially harmful for youth with schizophrenia.		

Sources: Brown et al., 2008; McClellan & Werry, 2001; McClellan, Stock & AACAP CQI, 2013.

# Pharmacological Treatments

Because there are few controlled studies on the efficacy and safety of-psychopharmacological medications for youth with EOS, pharmacological treatment of youth diagnosed with schizophrenia is modeled after treatment studies with adults (McClellan & Werry, 2001; Brown et al., 2008; Kodish & McClellan, 2008). Although there have been studies of these drugs, many are limited in their scope and external validity. Serious side effects include seizures and

neutropenia, a blood condition in which the cells that defend the body against bacterial infections (neutrophils) are significantly reduced (McClellan & Werry, 2001; Godwin & Braden, 2009). These adverse side effects have been shown to occur at a higher rate in youth than in adults (McClellan & Werry).

The most widely prescribed class of drugs for youth under 18 years of age are second-generation antipsychotics. Second generation antipsychotics show no significant difference in efficacy between first generation antipsychotics, but their side effects are far less severe, making them the preferred choice of treatment for youth (McClellan, Stock & AACAP CQI, 2013). The FDA has approved risperidone, aripiprazole, quetiapine, paliperidone, and olanzapine for the purposes of treating children over the age of 13, but these medications still do not meet the criteria for evidenced-based treatments (McClellan, Stock & AACAP CQI; Paglsberg et al., 2014).

One of the largest studies to date of the efficacy of antipsychotics in youth compared two second-generation antipsychotics (risperidone and olanzapine) to haloperidol, a conventional antipsychotic. After eight weeks of treatment, the study measured a treatment response in 88 percent of youth taking olanzapine and 74 percent in those taking risperidone, as compared to 53 percent in those taking haloperidol (Sikich, Hamer, Bashford, Sheitman & Lieberman, 2004). Clozapine also has documented efficacy in youth in over 15 studies (Brown et. al., 2008; McClellan & Werry, 2001; McClellan, Stock & AACAP CQI, 2013). However, owing to its potential side effects, clozapine is reserved for treatment in patients with two or more failed trials of a first-line antipsychotic agent. Before using clozapine, it is important to review the youth's clinical status and treatment history. Moreover, when using clozapine, systematic monitoring of side effects, including following established protocols for blood count monitoring, is required (McClellan, Stock & AACAP CQI, 2013).

A randomized clinical trial looking at therapies appropriate for EOS found that youth remained on olanzapine significantly longer than risperidone and haloperidol. Another study showed no difference in efficacy or tolerability of risperidone and quetiapine on first-onset psychosis (McClellan, Stock & AACAP CQI, 2013).

Long-term monitoring of therapy compliance and side effects is essential for any treatment regimen requiring antipsychotic agents (McClellan & Werry, 2001). A common side effect of atypical antipsychotics is weight gain, which can result in many general metabolic disorders in youth (Kowatch et al., 2005). Cognitive side effects, such as problems with word retrieval, working memory, and cognitive dulling, can also occur. Other side effects for both first- and second-generation antipsychotics include abnormal involuntary movements and neuroleptic malignant syndrome (McClellan & Werry; Brown et al., 2008). Youth may be at higher risk than adults for extrapyramidal side effects (i.e., repetitive, involuntary muscle movements or an undeniable urge to be moving). Because these medications may have serious side effects, parents and clinicians must educate themselves in order to make informed decisions, keeping the risks of side effects and potential adverse reactions in mind.

In addition to the side effects, there are different factors that go into choosing the correct medication for a youth with schizophrenia. Clinicians and families must make the best decision based on FDA recommendations, cost, clinician familiarity, patient profile, and family preference (McClellan, Stock & AACAP CQI, 2013).

Pharmacological treatment is considered first-line therapy for children with schizophrenia. However, it must be used in addition to psychotherapeutic interventions for a more holistic treatment approach with a higher rate of effectiveness (McClellan, Stock & AACAP CQI).

## Psychological Treatments

There are many different psychological treatment options for youth with schizophrenia. Although studies are limited and patient access can be an issue, there is significant evidence suggesting their efficacy (McClellan, Stock & AACAP CQI, 2013). A proper psychological treatment paired with medication can be extremely effective in improving a patient's functioning (emotionally, socially, and cognitively) and their overall cost of care (Penn et al., 2005). The incidence of re-hospitalization is also significantly reduced with an effective psychological treatment plan (McClellan, Stock & AACAP CQI). An integrated treatment protocol of medication, monitoring, and access to rehabilitation programs will help prevent relapse better than medication alone (*New York Times*, 2013).

The AACAP Practice Parameters state that the goal of therapy is both to help the youth return to a premorbid level of functioning (i.e., prior to the development of the disorder) and to promote the mastery of age-appropriate developmental tasks (McClellan & Werry, 2001). With the addition of these adjunctive psychotherapies, it is easier for youth to adhere to treatment protocols and remediate morbidity (McClellan, Stock & AACAP CQI, 2013). Family involvement in treatment for EOS is especially important because youth are usually dependent on their families (Brown et al., 2008). Evidence suggests that family involvement can make treatment more effective and decrease the amount of time a youth spends in institutional care (Lenior et al., 2001).

#### **Treatment Considerations**

Treatment protocols may vary, depending on the phase of illness (McClellan & Werry, 2001). Specialized educational programs and/or vocational training programs, such as adjunctive psychotherapies or cognitive remediation, may be crucial for some youth to address related cognitive and functional deficits (McClellan, Stock & AACAP CQI, 2013; McClellan & Werry, 2001). Some youth will likely require more intensive community support services. There are some cases in which the severity of symptoms necessitates long-term placement in a residential facility. However, as in treatment for all disorders in youth, the least restrictive setting option should always be utilized as appropriate. In addition to those treatments provided specifically for schizophrenia, other treatments may be needed to address comorbid conditions or other treatment implications, such as substance abuse, depression, and thoughts of suicide (McClellan & Werry). Treatment for schizophrenia is a lifelong process (NIMH, 2007).

Follow-up studies have shown that family acceptance, appropriate medication management, appropriate psychological treatment, and appropriate school placement are predictors of good response to treatment in youth with EOS (Findling, Boorady & Sporn, 2007; McClellan, Stock & AACAP CQI, 2013).

## **Unproven Treatments**

Psychodynamically-oriented therapies are considered to be potentially harmful for youth with schizophrenia; thus their use is not recommended (U.S. Department of Health and Human Services, 1999). Case studies have described the use of electroconvulsive therapy (ECT) for youth with treatment-refractory schizophrenia. The overall effectiveness of ECT in youth remains in question, and it has not been studied to the degree necessary to be considered evidence based. ECT should be a last effort after all other treatment options have been exhausted and after the cost to benefit ratio has been discussed in depth with the treating clinician (McClellan, Stock & AACAP CQI, 2013). Social skills training is also not currently supported as a treatment for EOS (Asarnow et al., 2004; Penn et al., 2004).

#### **Cultural Considerations**

When assessing, diagnosing, and treating youth with mental health disorders, clinicians should take into consideration the youth's cultural background. Unfortunately, little is known about cultural differences in the prevalence or presentation of EOS. However, research has shown that minority youth have a higher chance of being diagnosed with a behavior disorder or schizophrenia (DelBello, Lopez-Larson, Soutullo & Strakowski, 2001). In addition, in some cultures and religious groups, certain delusions and hallucinations (e.g., hearing or seeing religious figures or spirits) are part of a standard religious practice. When taken out of context, cultural or religious beliefs could be misinterpreted as possible psychosis (McClellan & Werry, 2001). To avoid misdiagnosis, a clinician should carefully assess minority youth, especially when the presenting complaint involves psychotic symptoms (Youngstrom, 2007). Garb suggests that, when assessing minority youth, clinicians should gather family history data at the symptom level, if possible, and be cautious about face value interpretation due to the potential for cultural bias (1998). Clinicians treating youth with EOS should also acknowledge family dynamics in developing treatment plans.

There is also a negative stigma against schizophrenia in society in general. Stigmas are defined as a negative misrepresentation of a group (Benbow, 2007). Negative stigmas surrounding the diagnosis of schizophrenia can deter individuals from seeking initial assessment and continuing care (Benbow). Schizophrenia is also grossly misunderstood in society (Owens, 2007). This lack of knowledge can lead to the limited advancement of those with schizophrenia, as many rely on preconceived notions of the illness to evaluate individuals suffering from schizophrenia (Link, Cullen, Frank & Wozniak, 1987; Schulze, 2008).

## **Overview for Families**

Schizophrenia is an illness that causes strange thinking and unusual behavior (AACAP, 2013). Schizophrenia in youth, or early-onset schizophrenia, is both uncommon and hard to recognize (AACAP). The source of schizophrenia is unknown, and it is a life-long disease (AACAP). Some early signs of the disorder include talking about strange fears and ideas, clinging to parents, and speaking incoherently or nonsensically (AACAP). Typically, the onset of the disease is slow and changes are gradual.

The symptoms of schizophrenia in children and adolescents differ from those in adults. They include but are not limited to:

- Hallucinations (the most common criteria for youth)
- Paranoia
- Odd behavior and speech
- Bizarre thoughts and ideas
- Inability to discern television and dreams from reality
- Extreme moodiness
- Withdrawn and increased isolation
- Decline in personal hygiene (AACAP, 2013).

Families should look for the symptoms listed above, but also realize that schizophrenia progresses in phases. Psychosis (a condition in which thought and emotions are so impaired that contact is lost with external reality) must be present prior to a diagnosis of schizophrenia.

<u>Prodromal Phase</u>: Before a child displays very obvious symptoms they may decline in any of the following ways:

- Social function
- Odd preoccupations
- Idiosyncratic behaviors
- Trouble in school
- A lack of self-care

## **Active Phase**

- Hallucinations
- Delusions
- Marked distortions in thinking
- Disturbances in behavior and feelings

## Residual Phase

- Listless
- Trouble concentrating
- Other symptoms similar to Prodromal Phase (CAMH, n.d.)

It should be noted that the active phase is often the most frightening phase to both the youth with schizophrenia and those closest to the youth (CAMH). Also, if a child does not respond to treatment and still exhibits symptoms, treatment should continue and alternative treatments should be explored (McDonnell & McClellan, 2007).

If families suspect that a child has schizophrenia, they should ask their family physician or pediatrician to refer them to a child or adolescent psychiatrist with special training in evaluating and diagnosing children with schizophrenia (AACAP, 2013).

## **Resources and Organizations**

## American Academy of Child and Adolescent Psychiatry (AACAP)

Facts for Families: Schizophrenia in Children

http://www.aacap.org/AACAP/Families\_and\_Youth/Facts\_for\_Families/FFF-Guide/Schizophrenia-In-Children-049.aspx

#### **Brain & Behavior Research Foundation**

https://www.bbrfoundation.org/

#### **Mental Health America (MHA)**

(formerly National Mental Health Association)

http://www.mentalhealthamerica.net

#### **National Alliance for Mental Illness (NAMI)**

Schizophrenia

https://www.nami.org/Learn-More/Mental-Health-Conditions/Schizophrenia

### **National Institute of Mental Health (NIMH)**

http://www.nimh.nih.gov

#### **Substance Abuse and Mental Health Services Administration (SAMHSA)**

National Mental Health Information Center

http://mentalhealth.samhsa.gov

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# POLAR AND RELATED DISORDERS

Introduction

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**Causes and Risk Factors** 

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#### Introduction

Bipolar and related disorders are characterized by shifts of mood with severe highs (mania) and extreme lows (depression). In a depressed episode, the child may have any or all of the symptoms of a depressive disorder. When in a manic episode, the child may be overactive, over talkative, and have a great deal of energy (American Psychiatric Association [APA], 2015). Depressive disorders are distinct from the bipolar and related disorders because they include an elevated mood component as well as a depressed mood state, the combination of which is reflected in the prefix bi, meaning "dual states" (Wilmshurst, 2014). The depressive disorders, in contrast, manifest a single (unipolar) emotional state of low positive affectivity characterized by sadness, lethargy, distress, and/or un-pleasurable engagement (Wilmshurt). The symptoms of bipolar and related disorders can damage relationships, cause problems at work or school, and even lead to suicide. Several studies have shown that up to 60 percent of adult patients diagnosed with bipolar and related disorders had onset of the disorder before age 21. Early-onset bipolar disorder can be a particularly severe form of the illness (Perlis et al., 2004), and evidence indicates that bipolar disorder in children may have a more severe course and poorer prognosis than bipolar disorder associated with older adolescents and adult-onset (Roberts, Bishop, & Rooney, 2008).

Once considered a disorder occurring only in adults, the rate of bipolar disorder diagnosis in youth has doubled in outpatient clinical settings, and quadrupled in community hospitals in the United States (Leibenluft & Rich, 2008). There has been a 40-fold increase of the diagnosis of bipolar disorder in children between 1995 and 2003 (Papolos & Bronsteen, 2013). There has also been an explosion of interest among researchers and clinicians in bipolar and related disorders in recent years.

## Recent Changes from the DSM-IV to the DSM-5

In 2013, the American Psychiatric Association released the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*). Bipolar disorders were separated from depressive disorders in the *DSM-5*, and the chapter "Bipolar and Related Disorders" was placed between "Schizophrenia Spectrum and Other Psychotic Disorders" and "Depressive Disorders." The APA made this change because it now views bipolar disorder as a bridge between psychotic and depressive disorders (APA, 2013a) based on recent research on symptoms, family history, and genetics (APA).

There are seven diagnoses included in the bipolar and related disorders section of the DSM-5:

- 1. Bipolar I disorder
- 2. Bipolar II disorder
- 3. Cyclothymic disorder
- 4. Substance/medication-induced bipolar and related disorder
- 5. Bipolar and related disorder due to another medical condition
- 6. Other specified bipolar and related disorder
- 7. Unspecified bipolar and related disorder

The term "bipolar disorder" may be used interchangeably with the term "bipolar and related disorders" when general observations and references are made in this section.

The *DSM-5* also modified the diagnostic criteria for bipolar disorder to promote earlier detection and accurate diagnoses. The diagnostic criteria focusing on manic and hypomanic (a more mild form of mania) episodes add emphasis to activity and energy changes along with mood (APA, 2013a). The *DSM-5* includes a new specifier, "with mixed features," that applies to episodes of mania or hypomania when depressive features are present, and to episodes of depression in the context of major depressive disorder or bipolar disorder when features of mania/hypomania are present (APA, 2013b). An additional specifier, "anxious distress," identifies patients with anxiety symptoms that are not part of the bipolar diagnostic criteria (APA, 2013b).

Additionally, the *DSM-5* adds and removes several diagnoses. "Bipolar disorder not otherwise specified" has been replaced by "bipolar and related disorder due to another medical condition," "other specified bipolar and related disorder," and "unspecified bipolar and related disorder." These diagnoses allow clinicians to further specify, if they so choose, the symptoms that characterize the bipolar disorder.

A new diagnosis present in the *DSM-5*, "disruptive mood dysregulation disorder," was established to prevent inappropriate bipolar disorder diagnoses in youth (APA, 2013a). Disruptive mood dysregulation disorder is discussed further in the depressive disorders section of this *Collection*.

The *DSM-5* is a manual for assessment and diagnosis of mental health disorders and does not include information for treatment of any disorder. In the future, more evidence supporting treatments of disorders with *DSM-5* classifications will be available as clinical studies utilizing *DSM-5* criteria are conducted. As a result, this *Collection* will reference studies that utilize *DSM-IV* diagnostic criteria to explain symptoms and treatments.

#### **Prevalence**

A meta-analysis of 12 epidemiological studies found an average rate of two percent for bipolar and related disorders in youths under age 19 (Jenkins et al., 2012). In outpatient clinical populations, evidence suggests prevalence estimates between 0.6 and 15 percent, depending on the diagnostic instrument, clinic specialization, and referral source (Jenkins et al.). Because the prevalence of bipolar disorder varies substantially by type of setting, it is important to consider the starting base rate in light of clinical context. Two published estimates indicated a base rate of six percent for bipolar and related disorders in an outpatient clinic (Jenskins et al.).

Table 1 outlines the prevalence of the various bipolar disorder categories in adult samples as contained in the *DSM-5*. Prevalence data on youth with bipolar disorder is limited because of the debate regarding the diagnosis. The *Diagnostic and Statistical Manual, Fourth Edition, Text Revised (DSM-IV-TR)* criteria prevalence is included, but not separated by diagnosis category.

Table 1

Prevalence of Bipolar and Related Disorders Categories

Disorder —	12 Month Prevalence		Male to Female
Disorder	In U.S.	Internationally	Ratio
Bipolar I Disorder	0.6%	0.0 - 0.6%	1.1:1
Bipolar II Disorder	0.8%	0.3%	
Cyclothymic Disorder  Lifetime  With mood disorders	0.4% - 1.0% 3.0% - 5.0%		1:1
DSM-IV Bipolar I, Bipolar II, and Bipolar Disorder Not Otherwise Specified in Youths 12 and older	2.7%	1.8%	

Source: APA, 2013a.

# **Categories**

The diagnostic class "bipolar and related disorders" describes disorders characterized by marked fluctuations in mood, activity, and behavior. As noted previously, there are seven primary diagnostic categories on the bipolar spectrum. The following are the diagnostic categories of bipolar and related disorders set forth in the *DSM-5*:

- 1. <u>Bipolar I disorder</u>: Requires a manic (or mixed) episode lasting at least one week, unless hospitalization is necessary. Depressive episodes are not required, but most youth experience major or minor episodes during their lifetime.
- 2. <u>Bipolar II disorder</u>: Requires major depressive episodes with at least one hypomanic episode (a lesser form of mania) lasting at least four days. There are no full manic or mixed manic episodes.

- 3. <u>Cyclothymic disorder</u>: Requires at least two years (one year in children and adolescents) of numerous periods of hypomanic symptoms that do not meet criteria for a hypomanic episode and numerous periods of depressive symptoms that do not meet criteria for a major depressive episode. Cyclothymic disorder is primarily a chronic, fluctuating mood disturbance.
- 4. <u>Substance/medication-induced bipolar and related disorder</u>: Requires that bipolar symptoms developed during or soon after substance exposure, intoxication, or withdrawal, and that the substance is capable of producing these symptoms.
- 5. <u>Bipolar and related disorder due to another medical condition</u>: Requires a persistent elevated, expansive, or irritable mood and high energy. No other mental disorder should be present that could explain the symptoms; instead, symptoms are a direct pathophysiological consequence of another medical condition.
- 6. Other specified bipolar and related disorder: Requires symptoms that do not meet the full criteria for any bipolar disorder but that cause significant distress. This includes short-duration hypomanic episodes and major depressive episodes, hypomanic episodes with insufficient symptoms or without accompanying major depressive episodes, or short-duration cyclothymia.
- 7. <u>Unspecified bipolar and related disorder</u>: This disorder is similar to "other specified bipolar and related disorder" but is diagnosed when the clinician chooses not to specify why symptoms do not meet bipolar criteria.

Because many individuals (particularly children and, to a lesser extent, adolescents) experience bipolar-like phenomena that do not meet the criteria for bipolar I, bipolar II, or cyclothymic disorder, the *DSM-5* included the "other specified bipolar and related disorder" category (APA, 2013a). The *DSM-5* also includes additional specifiers that can further define certain additional symptoms that may accompany a child's bipolar disorder. A new specifier "with mixed features" no longer requires the full criteria for both depressive and manic episodes. This specifier can also be added to manic episodes with depressive features or to depressive episodes with manic or hypomanic features (APA, 2013b).

The specifiers for bipolar and related disorders are as follows:

- With anxious distress:
- With mixed features;
- With rapid cycling;
- With melancholic features;
- With atypical features;
- With mood-congruent psychotic features;
- With mood-incongruent psychotic features;
- With catatonia;
- With peripartum onset; and
- With seasonal pattern.

For the most part, children with bipolar and related disorders present with similar symptoms to those of adults, but symptoms manifest in more developmentally appropriate ways. Symptoms may also include a decreased need for sleep, racing thoughts or a sense that thoughts are out of control, rapid and often pressured speech, increased goal-directed activities or projects, hypersexuality, reckless behaviors and risk-taking, and delusions of grandeur (Bernstein, 2017).

In adolescents, mania is commonly associated with psychotic symptoms, rapidly changing moods, and mixed manic and depressive features (Pavuluri, Birmaher, & Naylor, 2005). Mania in younger children is usually defined by erratic changes in mood, energy levels, and behavior. Irritability and mixed manic/depressive episodes are usually more common than euphoria (McClellan et al., 2007).

Unlike what is noted in adults, well-defined and discrete episodes of abnormal mood are often missing in children and adolescents with this disorder. Special considerations are necessary to detect the diagnosis in children. Since children of the same chronological age may be at different developmental stages, it is difficult to define with precision what is normal or expected at any given point (APA, 2013a). Therefore, each child should be judged according to his or her own baseline. Due to sparse evidence of the diagnostic validity of bipolar disorder in young children, the American Academy of Child and Adolescent Psychiatry (AACAP) recommends extreme caution when diagnosing bipolar disorder in preschool age children (McClellan et al., 2007). Misdiagnosis can lead to unnecessary or too aggressive pharmacological treatment.

#### **Causes and Risk Factors**

Family history is one of the strongest and most consistent risk factors for bipolar disorders. There is a 10-fold increased risk, on average, among adult relatives of individuals with bipolar I and bipolar II disorders (APA, 2013a). The degree of risk increases with degree of kinship. According to Youngstrom (2007), out of 100 articles that discussed more than 30 risk factors associated with bipolar disorder, family history was the only factor significant enough to warrant clinical interpretation. The child of a bipolar parent is four times more likely to develop bipolar disorder than a child of a non-bipolar parent (Miklowitz & Johnson, 2006). There is also an overlap in genetic heritability between bipolar and certain other disorders, such as schizophrenia (15 percent) and depression (10 percent) (Brooks, 2013).

Other risk factors associated with the development of bipolar disorder are:

- Psychosocial stressors that interact with biological and/or genetic predisposition in eliciting episodes (Roberts, Bishop & Rooney, 2008);
- Poor peer relationships (Geller et al., 2000); and
- Early traumatic life events, which can lead to a more pernicious course (Leverich & Post, 2006).

Bipolar and related disorders present differently by economic status and is more common in high-income (1.4%) than low-income (0.7%) families (APA, 2013a). Research has also shown that males tend to exhibit mania more often, whereas females are more likely to present with depression (Duax et al., 2007).

Gestational influenza may also cause, or trigger, bipolar disorder in children. The increased risk to a child whose mother had influenza during pregnancy is four times that of a child whose mother did not (Louden, 2013). This connection does not carry over to other disorders of maternal respiration (Louden). Additional research revealed a similar link between gestational influenza and schizophrenia, further linking the two disorders and further supporting the necessity of influenza prevention in women who may become pregnant (Brown et al., 2004).

#### Assessment

Proper assessment of bipolar disorder in children is essential to early diagnosis, intervention, and treatment. Evidence has shown that, although symptoms may appear very early in a child, there is an estimated six-year delay in diagnosis, on average (Dagani et al., 2017). In adolescents, this delay is often longer because moodiness is sometimes mistaken by parents and doctors for the emotional ups and downs typical of the teenage years. In addition, mental health clinicians are not always able to distinguish the depressed phase of bipolar disorder from other types of depression.

Early intervention may lead to a better prognosis. Although no information on early intervention is available in the bipolar disorder literature, adult studies have found that a longer delay from the first appearance of symptoms to treatment was associated with an increase in hospitalizations, a decrease in social adjustment, and a greater risk of suicidal behaviors (Goldberg & Ernst, 2002).

There are a number of red flags that should trigger assessment for a possible bipolar diagnosis. Even though youth exhibiting these red flags often will not have a bipolar disorder (Youngstrom et al., 2012), they should still be assessed, especially if they have two or three indicators. Red flags are summarized in Table 2.

The AACAP Practice Parameters for bipolar disorder recommend a comprehensive, multi-informant assessment procedure. Clinicians should attempt to acquire assessment information from youth, parents, and teachers (McClellan et al., 2007). During the initial assessment period, clinicians should obtain a thorough family medical and psychological history, and choose both broadband (general screening tools) and narrowband measures (specific to the disorder) in order to rule in/out other possible diagnoses or comorbid disorders. Most youth with bipolar disorder have at least one other co-occurring disorder.

Bipolar disorder can often be confused with attention-deficit/hyperactivity disorder (ADHD) and conduct disorder due to the existence of overlapping symptoms (Wilmshurt, 2014). Children or adolescents who seem depressed and also demonstrate symptoms that resemble those of ADHD but are more severe (excessive temper outbursts, rapid mood swings) should be evaluated for the existence of a bipolar or related disorder, especially if family history is positive for the disorder. Misdiagnosis of major depressive disorder or ADHD and subsequent treatment with antidepressants or psychostimulants can cause a manic episode for youth with bipolar disorder (DelBello et al., 2001). Unnecessary exposure to medications that have not been well-studied in youth can also lead to serious side effects (Findling et al., 2004). Assessment should also include measures of hypomanic/manic and depressed symptoms (Youngstrom et al., 2012).

Table 2

Red Flags that Trigger Assessment for Bipolar Disorder

Red Flag	Description	Reason
Family history of bipolar disorder	Bipolar disorder has a genetic contribution; family environment can amplify risk and affect treatment adherence and relapse	Five to 10 times increase for 1 <sup>st</sup> degree relative; 2.5 to 5 times for 2 <sup>nd</sup> degree relative; 2 times for "fuzzy" bipolar disorder in relative
Early onset depression	Onset less than 24 years of age; also, treatment resistant, recurrent, or atypical depression may be more likely to be bipolar	First clinical episode is often depression; 20% to 30% of depression ultimately shows a bipolar course
Antidepressant-coincident mania	Manic symptoms while being treated with antidepressants	The FDA recommends assessing for hypomania and family history of bipolar disorder before prescribing antidepressants
Episodic mood lability (marked fluctuation of mood)	Rapid switching between depressive and manic symptoms, depressive and manic symptoms at the same time	Common presentation; multiple episodes more suggestive of mood diagnosis
Episodic aggressive behavior	Episodic, high-energy, not instrumental or planned, reactive	Not specific to bipolar disorder but common
Psychotic features	True delusions/hallucinations in the context of mood	Delusions/hallucinations common during mood episode; bipolar more common as source of psychosis than schizophrenia in children
Sleep disturbance	Decreased need for sleep; less sleep but maintains high energy	More specific to bipolar disorder; indicates sleep hygiene component of treatment

Source: Youngstrom, et al., 2012.

One of the first steps in assessment should include an examination by a primary care provider to rule out any medical reason for the youth's change from normal behavior. Many medical conditions, such as hyperthyroidism, epilepsy, and head trauma, can induce mania or resemble symptoms of mania (Fields & Fristad, 2008). Once medical conditions have been ruled out, a clinician should attempt to gain a longitudinal perspective to document the course of the disorder. Obtaining a baseline for normal behavior is important to determine a meaningful change in this behavior. Having parents complete a mood log, in which they track their child's mood and energy for a certain number of weeks, is an effective way for a clinician to determine specific mood episodes and whether a child meets time-length criteria for specific bipolar

disorder symptoms (Youngstrom, 2007). Ongoing assessment and reevaluation after the initial diagnosis is critical in bipolar disorder diagnosis (Youngstrom et al., 2005).

Some of the broadband and narrowband assessment tools available for clinicians to use in the assessment of bipolar disorder are:

- Behavior checklists, such as Achenbach's Child Behavior Checklist (CBCL) (Achenbach, 1991);
- Clinical rating scales like the K-SADS-Mania Rating Scale (K-MRS) (Axelson et al., 2003), Child Mania Rating Scale (CMRS), General Behavior Inventory (GBI), or the Young Mania Rating Scale (Young et al., 1978);
- Mood rating scales, like the Mood Disorder Questionnaire for Bipolar Disorders in Adolescents (MDQ-A); and
- WASH-U-KSADS (Geller et al., 2001), a semi-structured interview with an expanded mania symptoms section.

The Externalizing Scale score on the CBCL is a useful screening tool, evidenced across multiple studies, in that it allows clinicians to screen for bipolar disorder quickly (Kahana et al., 2003; Youngstrom et al., 2004; Youngstrom, Youngstrom, & Starr, 2005). Although the scale score is sensitive to bipolar disorder, it is not specific due to the lack of a mania scale. Because of this, low Externalizing Scale scores usually help clinicians to rule out bipolar disorder as a diagnosis (Youngstrom, 2007). A high score, however, does not "rule in" a child; instead, it suggests the need for further bipolar disorder diagnostic assessment. The measure is a screening tool and, due to its lack of specificity, should not be the sole basis for a bipolar disorder diagnosis. Youngstrom also recommends adding a mania scale like the GBI, CMRS, or MDQ-A to assess mania in children for whom a bipolar disorder diagnosis is suspected (Youngstrom, et al., 2012). Table 3 lists the suggested assessment tools for bipolar and related disorders.

Knowledge of how developmental and cultural factors impact assessment and diagnosis is crucial to proper assessment. In youth, developmental issues and age-appropriate behavior must be considered in order for the clinician to interpret clinical data. It is also imperative that the clinician assesses not only symptoms, but also functional impairment.

Ongoing assessment of suicide risk is important due to the high risk of suicide attempts among youth with bipolar disorder. The lifetime risk of suicide in all individuals with bipolar disorder is estimated to be at least 15 times that of the general population (APA, 2013a). Bipolar disorder may account for one-quarter of all completed suicides (APA). Estimates show that 25 to 50 percent of youth with bipolar disorder will attempt suicide, and 20 percent will succeed (Faust, Walker & Sands, 2006). However, more recent literature on evidence-based assessment of bipolar and related disorders notes that these risks may be over-estimated based on the desire to avert risk (Youngstrom et al., 2012). A review of suicide assessment tools is provided in the "Youth Suicide" section of the *Collection*.

Table 3
Suggested Assessment Tools

Measure Type	Name of Measure	Who Completes	Data Generated
Clinical interview	Washington University version of the Kiddie-Schedule for Affective Disorders and Schizophrenia	Clinician with youth & parent	Diagnosis
Clinical interview	The Children's Interview for Psychiatric Syndromes (ChIPS)	Clinician with youth & parent	Diagnosis
Clinical interview	Mini-International Neuropsychiatric Interview (MINI)	Parent	Diagnosis
Rating scale	Mood Disorder Questionnaire (MDQ)	Parent or youth	Symptom ratings
Behavior checklist	Child Behavior Checklist (CBCL)	Parent	Syndrome scale scores; Competence scores
Behavior checklist	Youth Self-Report (YSR)	Youth	Syndrome scale scores; Competence scores
Rating scale	General Behavior Inventory (GBI)	Parent or youth	Symptom ratings
Rating scale	Young Mania Rating Scale	Clinician or parent	Symptom ratings
Rating scale	Child Mania Rating Scale	Parent	Symptom ratings
Rating scale	Pediatric Quality of Life Inventory (PedsQL)	Parent or youth	Child functioning ratings

Sources: Youngstrom, 2007; Youngstrom et al., 2012.

# Comorbidity

Comorbidity complicates diagnosis because youth assessed for bipolar disorder frequently meet criteria for multiple psychiatric disorders (Jenkins et al., 2012). It is not uncommon for clinicians to focus on the comorbid condition and inadvertently neglect the bipolar disorder. Similar to the literature on adults, various research studies have shown that children and adolescents suffering from bipolar and related disorders have very high rates of comorbidity with other psychological disorders (Jenkins et al., 2012; Kessler, 1999; Kowatch et al., 2005), the most common being

ADHD (e.g., Biederman et al., 2004; Masi et al., 2006; Youngstrom et al., 2005), oppositional defiant disorder (ODD) (Youngstrom et al., 2005), conduct disorder (Lewinsohn et al., 2002), and anxiety disorders (Harpold et al., 2005). Psychosis has also been shown to be comorbid with bipolar disorder (Biederman et al., 2004).

Evidence has shown that as many as 60 to 90 percent of youth with bipolar disorder have comorbid ADHD (Axelson et al., 2006; Joshi & Wilens, 2009), and as many as 78 percent of youth have comorbid anxiety disorders (Harpold et al., 2005). Youth with comorbid ADHD and/or anxiety disorders often show greater functional impairment and a worse prognosis (Youngstrom, 2007). Clinicians should take care to ensure that comorbid disorders are diagnosed because misattributing symptoms can lead to inappropriate diagnosis or utilization of pharmacotherapy (Joshi & Wilens).

Families should be cognizant of the possibility that bipolar may accompany substance use disorder (APA, 2013a). One in three teens with bipolar and related disorders developed substance abuse within four years of a study tracking youth with bipolar. The following are the top predictors of substance abuse in bipolar adolescents:

- Repeated alcohol experimentation
- Cannabis experimentation
- Oppositional defiant disorder
- Panic disorder
- Family history of substance abuse
- Low family cohesiveness
- Absence of antidepressant treatment (Goldstein et al., 2013)

Recreational substance use can be very dangerous for individuals with bipolar and related disorders (Goldstein, et al.).

#### **Treatments**

Available practice guidelines for bipolar and related disorders in youth are somewhat outdated. This is because of the lack of clinical trials on which to base treatment recommendations (Chang, 2016). Accordingly, treatment recommendations for youth incorporate findings from the small number of available studies, utilize recommendations from adult studies, and incorporate clinical experience. Currently, there are no pharmacological or psychosocial therapies with enough evidence in youth samples to meet the standards for evidence-based treatments, although the treatments discussed in this section have been shown to be probably efficacious (what seems to work) (Chambless & Hollon, as cited by Youngstrom, 2007).

The AACAP Practice Parameters for treatment of early-onset bipolar disorder, which were published in 2007, provide a comprehensive, multimodal combination of both psychopharmacology and psychosocial therapies (Meers, & Fristad, 2017; McClellan et al., 2007). The AACAP Practice Parameters also advise that treatment should be tailored to the individual and based on several different factors, including treatment setting, the chronic nature of the disorder, the age of the child, and the family environment. The goals of therapy are to reduce symptoms, educate about the illness, and promote adherence to treatment, which works

towards preventing relapse and promotes normal growth and development in youth with bipolar disorder (McClellan et al.).

Table 4 summarizes the treatments for bipolar and related disorders.

Table 4
Summary of Treatments for Bipolar and Related Disorders

What Works			
There are no evidence-based practices at this time.			
What Seems to Work			
Psychopharmacological treatment (medication)	Mood stablizers/Anticonvulsants Second-generation antipsychotics		
Family-focused psychoeducational therapy (FFT)	Helps youth make sense of their illness and accept it and also to better understand use of medication. Also helps to manage stress, reduce negative life events, and promote a positive family environment.		
Child- and family-focused cognitive behavioral therapy (CFF-CBT)	Emphasizes individual psychotherapy with youth and parents, parent training and support, and family therapy.		
Multifamily psychoeducation groups (MFPG)	Youth and parent group therapy have been shown to increase parental knowledge, promote greater access to services, and increase parental social support for youth.		
Not Adequately Tested			
Interpersonal social rhythm therapy (IPSRT)	Works to minimize the effects of life stressors by helping youth establish regular patterns of sleep, exercise, and social interactions		
Omega-3 fatty acids	Unclear if supplementation helps with depressive symptoms when used in conjunction with other treatments		
Topiramate Oxcarbazepine	Anticonvulsants; not proven to be effective in youth or adults		
Dialectical behavior therapy (DBT)	Family skills training and individual therapy; not proven to help with mania or interpersonal functioning		

Sources: Fristad, Goldberg-Arnold & Gavazzi, 2002; Fristad, Gavazzi & Mackinaw-Koons, 2003; Miklowitz et al., 2004; Pavuluri et al., 2004; Roberts, Bishop, & Rooney, 2008; Brown et al., 2008; Leibenluft & Rich, 2008; American Psychological Association [APA] Division 53, 2013; Fristad & MacPherson, 2014.

## Pharmacological Treatments

The goal of pharmacological treatment for bipolar and related disorders is to immediately reduce the severity of symptoms (Leibenluft & Rich, 2008). Pharmacotherapy, combined with psychotherapy, offers the best chance for symptom recovery. However, because few large-scale prospective studies have examined pharmacologic treatment for youth with bipolar and related

disorders, many of these medications are used without specific FDA approval for youth (Washburn, West, & Heil, 2011). Accordingly, pharmacological treatment is modeled after treatment experiences with adults (Washburn, West, & Heil; Roberts, Bishop, & Rooney, 2008).

Although the number of studies that include children and adolescents remains quite small, preliminary evidence suggests that a combination of mood stabilizers/anticonvulsants and second generation antipsychotics have been shown effective in treating acute symptoms of bipolar disorder and for stabilization of symptoms for up to six months after the studies were complete (Fitzgerald & Pavuluri, 2015; Miklowitz & Johnson, 2006; Pavuluri, Birmaher & Naylor, 2005). The AACAP Practice Parameters suggest that treatment for bipolar disorder begin with lithium, another anticonvulsant/mood stabilizer, or an atypical antipsychotic that has been approved by the FDA for bipolar disorder in adults (McClellan et al., 2007).

Lithium is currently the most extensively studied medication for use with bipolar disorder (Findling & Pavuluri, 2008; Kafantaris et al., 2001, 2003; Pavuluri, Birmaher, & Naylor 2005; Hamrin & Iennaco, 2010). Lithium has been found to be effective in approximately 60-70 percent of adolescents and children with bipolar disorder and remains the first-line therapy in many settings (Bernstein, 2017). However, youth experience the same safety problems with lithium that adults may experience, such as toxicity and impairment of renal and thyroid functioning (Geller & Luby, 1997; Brauser, 2012). Lithium is not recommended for families unable to keep regular appointments, which are necessary to ensure monitoring of serum lithium levels in the blood and to manage conflicting side effects (Brauser). Relapse is also high for those youth who discontinue the medication.

When employing pharmacotherapy, mood stabilization is the first priority and should be addressed before the addition of stimulants to treat attentional difficulties (Fitzgerald & Pavuluri, 2015). Through the use of a medication algorithm, the addition of subsequent medications to treat residual symptoms or comorbid conditions is a recommended best practice, but only after primary affect dysregulation (emotional impairment) has been addressed. Table 4 divides the psychopharmacological treatments for bipolar disorder into two categories: What Works and What Seems to Work.

Youth diagnosed with bipolar disorder and comorbid ADHD respond less favorably to lithium treatment than youth who do not have ADHD. This may point to a genetic difference in the two populations (Joshi & Wilens, 2009). However, mood stabilizers show better results than stimulants in youth with bipolar disorder and comorbid ADHD.

The following is taken from a medication algorithm developed by Pavuluri, 2014. In establishing a plan for mood stabilization, four things are important to consider. First, a history should be obtained that details which medications worsened the youth's clinical status in the past, which were ineffective, and which were helpful. Second, the youth should be rapidly weaned off all ineffective medications. Third, selective serotonin reuptake inhibitors (SSRIs) should be discontinued. Despite compelling data in pediatric populations that shows that SSRIs worsen the symptoms of bipolar disorder either by switching or worsening mania, many children with bipolar or related disorders are on substantial doses of SSRIs. Bipolar and related disorders typically present with mixed or dysphoric states, and many physicians tune into depressive symptoms at the cost of worsening the clinical state. Fourth, stimulants should be discontinued.

Mood stabilization is the primary treatment objective and should be attained prior to controlling symptoms of ADHD. However, if parents report that stimulants have been helpful, the clinician may elect to continue stimulants at the lowest possible doses and, preferably, in long acting form.

Unfortunately, mood stabilizers and atypical antipsychotics have a number of adverse side effects, including, but not limited to, weight gain, drowsiness, decreased motor activity, constipation, increased salivation, rigidity, and dystonia (Fleischhaker et al., as cited by Meers & Fristad, 2017). It is very important that children on these medications be monitored for the development of serious side effects. These side effects need to be weighed against the dangers of the manic-depressive illness itself.

## **Psychosocial Treatments**

Although no psychosocial treatments for bipolar disorder are considered evidence-based (Fristad, & MacPherson, 2014; Chambless & Hollon, 1998), recent evidence has shown that family-focused psychoeducational therapy (FFT) (Fristad, & MacPherson; Miklowitz et al., 2004), child- and family-focused cognitive behavioral therapy (CFF-CBT) (Pavuluri et al., 2004), and multifamily psychoeducation groups (MFPG) (Fristad, Goldberg-Arnold, & Gavazzi, 2002; Fristad, Gavazzi, & Mackinaw-Koons, 2003) show promise as adjunctive treatments to pharmacological treatment (Youngstrom, 2007). These three treatments have demonstrated symptom improvement and increased functioning in youth with bipolar disorder. The rationale behind these family-focused treatments are to give youth with bipolar disorder and their families knowledge and skills that could help limit the debilitating cycles of relapse and impairment that are characteristic of this disorder (Fristad, 2016).

## Unproven Treatments

Topiramate and oxcarbazepine, both anticonvulsants, have not been proven to be effective in the treatment of bipolar and related disorders in youth, which is consistent with findings from adult studies (Fitzgerald & Pavuluri, 2015). Interpersonal social rhythm therapy (IPSRT) (Frank, Swartz, & Kupfer, 2000) has shown some evidence of support in adult studies. IPSRT works to minimize the effects of life stressors by helping youth establish regular patterns of sleep, exercise, and social interactions (Leibenluft & Rich, 2008). There is no current evidence of its usefulness in bipolar and related disorders, but current research is studying a version of IPSRT for bipolar and related disorders in youth. A pilot open trial of IPSRT found both statistically and clinically significant improvements in manic, depressive, and general psychiatric symptoms (Fristad & MacPherson, 2014). However, IPSRT has not yet been tested sufficiently to assert that it is evidence-based.

Dialectical behavior therapy (DBT) consists of 24 weekly and 12 bimonthly 60-minute sessions alternating between family skills training and individual therapy, with as-needed telephone coaching. An open trial of one year of DBT and pharmacotherapy (managed by psychiatrists following treatment guidelines at a specialty outpatient clinic) for 10 adolescents aged 14 to 18 with bipolar and related disorders found that, although adolescents demonstrated significant post-treatment improvement in suicidality, emotion dysregulation, and depression, there were no significant improvements in mania or interpersonal functioning, and no differences in number of medications prescribed (Fristad & MacPherson, 2014).

More recently, attention has turned to complementary and alternative medicines because they are associated with fewer side effects. There is growing evidence for the use of omega-3 fatty acids in the treatment of bipolar and related disorders and mood disorders (Meers & Fristad, 2017). Omega-3 has been shown to be more effective than placebo for depressive symptoms in adults and youth (Osher & Belmaker, as cited by Meers & Fristad). Although promising, these treatments have yet to acquire the extent of evidence available for the first-line pharmacotherapy interventions discussed earlier. However, available evidence does indicate that supplementation might be a safe and effective adjunct to pharmacotherapy and psychotherapy (Fristad, 2016).

## **Cultural Considerations**

Unfortunately, little is available in the bipolar and related disorders literature about cultural differences in the prevalence or presentation of the disorder. Small sample sizes in treatment studies have not allowed for comparisons based on racial or ethnic groups (Brown et al., 2008).

However, when assessing, diagnosing, and treating youth with mental health disorders, it is imperative that a clinician take into consideration the youth's cultural background. Different cultures may have different beliefs about psychological issues, which should inform clinical judgment and decision-making. In Western cultures, people generally talk about their moods or feelings, whereas in many Eastern cultures, people refer to physical pain. Due to these differences, when assessing minority youth, clinicians should gather family history data at the symptom level, if possible, and be cautious about face value interpretation due to the potential for cultural bias (Garb, 1998).

#### Overview for Families

Families of children with bipolar disorder often notice the child has intense and extreme changes in mood and behavior. This may include the child varying between being excited, silly, and very sad. Children and youth with bipolar and related disorders experience unusual mood changes. The two "poles," or extreme moods, of bipolar disorder are mania and depression. When children with bipolar disorder feel very happy or "up" and are much more active than usual, they are experiencing mania. A manic episode is a period of abnormally and persistently elevated mood. The child exhibits an increase in goal-directed activity or energy that lasts at least one week (APA, 2013a). Mania is often described as a period of euphoria or excessive cheerfulness, and often it is easily recognized (APA). When the same child feels very sad and "down" and is much less active than usual, he or she is experiencing depression. Bipolar symptoms are more powerful than the normal mood changes every youth experiences. Bipolar and related disorders can cause a youth to struggle in school or with friends and family members.

The causes of bipolar disorder aren't always clear, and scientists are continually researching possible causes and risk factors (NIMH, 2008a; NIMH, 2008b). Experts believe that bipolar and related disorders can be caused by several things, including:

- Genetics: A child with a parent or sibling with bipolar disorder are more likely to get the illness than other children
- Brain structure and function
- Anxiety disorders

Additionally, children with a family history of schizophrenia are also at risk, as the genetic cause of both bipolar and schizophrenia are likely linked (APA, 2013a).

Bipolar disorder has several symptoms that vary according to the mood episode, or mood changes, the youth experiences. Mood episodes can last one to two weeks or longer, and the symptoms last most of the day, almost every day. Manic episodes are characterized by feeling very happy or "up" and being much more active than usual. Depressive episodes occur when the youth feels very sad, "down," and is much less active than usual. Some episodes may be mixed episodes, including both up and down symptoms. Children with bipolar disorder may have more mixed episodes than adults with bipolar. Signs to look for when a child or adolescent is experiencing a manic episode include:

- Feels very happy or acting silly, both of which are unusual
- Has a short temper
- Talks very fast about different things
- Struggles to focus
- Talks and thinks about sex more frequently
- Takes abnormal risks

Signs to look for when a child or adolescent is experiencing a depressive episode include:

- Feels very sad
- Complains about pain, including stomach aches and headaches
- Sleeps too little or too much
- Feels guilt and worthlessness
- Overeats or doesn't eat enough
- Has little energy or interest in fun activities
- Thinks about death or suicide

Table 5 describes some of the symptoms of both mania and depression. The list is not exhaustive.

Table 5

Manic and Depressive Symptoms

Manic Symptoms	Depressive Symptoms
<ul> <li>Severe changes in mood to either unusually happy or silly, or very irritable, angry, or agitated</li> <li>Unrealistic highs in self-esteem</li> <li>Greatly increased energy and the ability to operate on little or no sleep for days</li> <li>Increased talking</li> <li>Increasingly distracted, moving from one thing to the next</li> <li>Repeating high risk behavior</li> </ul>	<ul> <li>Irritability, persistent sadness, frequent crying</li> <li>Thoughts of death or suicide</li> <li>No longer enjoys favorite activities</li> <li>Frequent complaints of physical illness, like headaches</li> <li>Decreased energy level</li> <li>Major change in eating and sleeping patterns</li> </ul>

Source: AACAP, 2008.

Children and adolescents with bipolar disorder may have other problems as well. When disorders occur at the same time, they are called "comorbid." Comorbid disorders can include:

- Substance abuse
- Attention-deficit/hyperactivity disorder (ADHD)
- Anxiety disorders, like separation anxiety
- Other mental illnesses, including depression (NIMH, 2008a; NIMH 2008b).

Youth with bipolar and related disorders can effectively be treated through a combination of educating the patient and family, medicine, and psychotherapy (AACAP, 2008). Therefore, a thorough evaluation by a child and adolescent psychiatrist should be sought when symptoms are exhibited.

# **Resources and Organizations**

#### American Academy of Child & Adolescent Psychiatry (AACAP)

http://www.aacap.org

Bipolar Disorder: Parents' Medication Guide for Bipolar Disorder in Children, & Adolescents http://www.parentsmedguide.org/bipolarmedicationguide.pdf

#### **American Psychiatric Association (APA)**

https://www.psychiatry.org

#### American Psychological Association (APA)

http://www.apa.org/

#### **Association for Behavioral and Cognitive Therapies (ABCT)**

http://www.abct.org/Home/

### **Effective Child Therapy**

http://effectivechildtherapy.org/

# **Healthy Place**

Medication and Therapy for Treating Bipolar Disorder in Children

https://www.healthyplace.com/bipolar-disorder/articles/medication-and-therapy-for-treating-bipolar-disorder-in-children/other-medications-for-bipolar-disorder/

#### **American Foundation for Suicide Prevention (AFSP)**

https://afsp.org/

#### **Anxiety and Depression Association of America (ADAA)**

https://adaa.org/

#### Depression and Bipolar Support Alliance (DBSA)

(formerly the National Depressive and Manic Depressive Association)

http://www.dbsalliance.org

#### **Juvenile Bipolar Research Foundation**

https://www.jbrf.org/about-jbrf

#### **Mental Health America (MHA)**

(formerly National Mental Health Association)

Bipolar Disorder in Children

http://www.mentalhealthamerica.net/conditions/bipolar-disorder-children

#### **National Alliance on Mental Illness (NAMI)**

Bipolar Disorder

https://www.nami.org/Learn-More/Mental-Health-Conditions/Bipolar-Disorder/Support

#### **National Institute of Mental Health (NIMH)**

Bipolar Disorder in Children and Teens

https://www.nimh.nih.gov/health/publications/bipolar-disorder-in-children-and-teens/index.shtml

# **Ryan Licht Sang Bipolar Foundation**

http://www.ryanlichtsangbipolarfoundation.org/site/c.ltJZJ8MMIsE/b.2107311/k.BCD3/Home.htm

#### **University of North Carolina Department of Psychiatry**

UNC Center for Excellence in Community Mental Health—Bipolar Disorder

http://www.med.unc.edu/psych/cecmh/patients/clinics-programs/patient-client-information-and-resources/copy\_of\_clients-and-familes-resources/a-family-guide-to-severe-mental-illness/ii-what-are-mood-disorders/bipolar-disorder

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# DEPRESSIVE DISORDERS

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#### Introduction

Like adults, children and adolescents experience depression with the accompanying feelings of hopelessness, guilt, or sadness. It is estimated that 15 to 20 percent of all youth experience depression by the age of 18 (Klein, Torpey, & Bufferd, 2008). The risk is greater for girls; beginning in early adolescence, females are 1.5 to 3 times more likely to experience depression than males (American Psychiatric Association [APA], 2013a). Common symptoms of depression include the following:

- Sadness or dejected mood
- Irritability
- Decreased energy and interest in activities
- Loss of feelings of pleasure
- Changes in sleep and appetite
- Difficulty thinking clearly, making decisions, and concentrating
- Lethargy and/or fidgetiness
- Feelings of hopelessness, worthlessness, and/or guilt
- Thoughts of death or suicide (APA, 2013a)

Depression in children and adolescents can manifest in different ways than it does in adults (American Academy of Child & Adolescent Psychiatry [AACAP], 2008). For instance, in adolescents, an irritable mood rather than a sad or dejected mood often predominates. Other signs include but are not limited to:

- Lack of interest in activities that once brought joy
- Frequent sadness or crying
- Newfound social isolation
- Low self-esteem
- Thoughts or expression of self-destructive behavior (AACAP)

Depressed youth may not always seem sad and can act out in ways that get them in trouble at school. It should also be noted that depression often runs in families (AACAP).

Because depressive disorders can result in suicide, depression among children and adolescents is of grave concern. Approximately 60 percent of adolescents with depression have recurrences throughout adulthood (Clark, Jansen, & Cloy, 2012). The emotional and behavioral dysfunction associated with these mood disorders can cause impairments across areas of functioning, including academic and social arenas.

# Recent Changes from the DSM-IV to the DSM-5

In 2013, the American Psychiatric Association (APA) released the fifth edition of the *Diagnostic* and *Statistical Manual of Mental Disorders* (*DSM-5*) to replace the fourth text revision (*DSM-IV-TR*). Depressive disorders included in the *DSM-5* are listed below:

- Disruptive mood dysregulation disorder
- Major depressive disorder
- Persistent depressive disorder (dysthymia)
- Premenstrual dysphoric disorder
- Substance/medication-induced depressive disorder
- Depressive disorder due to another medical condition
- Other specified depressive disorder
- Unspecified depressive disorder (APA, 2013a)

The common feature of all of these disorders is the presence of sad, empty, or irritable mood, accompanied by somatic and cognitive changes that significantly affect the individual's capacity to function (APA, 2013a).

One major area of change in the *DSM-5* is that the *DSM-5* chapter on depressive disorders has been separated from the previous chapter, "Bipolar and Related Disorders." Furthermore, the *DSM-5* renamed dysthymia to persistent depressive disorder (dysthymia), and joined the prior description of dysthymia with chronic major depressive disorder (APA, 2013b). Another significant change in the *DSM-5* is the addition of new depressive disorders, including disruptive mood dysregulation disorder and premenstrual dysphoric disorder. Disruptive mood dysregulation disorder is a diagnosis reserved for children from six to 18 years of age who show persistent irritability and frequent episodes of extremely out-of-control behavior. This new

diagnosis was added to address concerns about the potential over-diagnosis and overtreatment of bipolar disorder in children (APA, 2013a).

An additional change in the *DSM-5* is that premenstrual dysphoric disorder, which previously appeared in Appendix B of the *DSM-IV-TR* under "Criteria Sets and Axes Provided for Further Study," has been moved to the main body of the *DSM-5*. Premenstrual dysphoric disorder is a more severe form of premenstrual syndrome (PMS), which is characterized by strong emotional symptoms such as depression, anxiety, moodiness, and irritability (APA).

The *DSM-5* also removed what was known as the bereavement exclusion for major depressive episodes (APA, 2013b). Previously, any major depressive episode following the death of a loved one that lasted less than two months was not classified as a major depressive episode. By leaving out this exclusion, the *DSM-5* acknowledges that there is no scientifically valid reason for treating the grieving process differently from any other stressor that might trigger a depressive episode (APA). The *DSM-5* includes information to assist clinicians in distinguishing between normal grief and a major depressive episode so they can make better decisions about whether a particular individual may benefit from treatment.

The *DSM-5* has also added some new specifiers to further clarify diagnoses. These specifiers are described below.

- With mixed features: This new specifier can be present in bipolar and depressive disorders. It allows for the presence of manic symptoms as part of the depression diagnosis in patients who do not meet the full criteria for a manic episode.
- With anxious distress: This specifier was added because the presence of anxiety can impact prognosis, treatment choices, and the patient's response to them.

The *DSM-5* is a manual for assessment and diagnosis of mental health disorders and does not include information for treatment of any disorder. In the future, more evidence supporting treatments of disorders with *DSM-5* classifications will be available as clinical studies using *DSM-5* criteria are conducted. As a result, this *Collection* will reference studies that utilize *DSM-IV* diagnostic criteria to explain symptoms and treatments.

# **Categories**

The following are descriptions of the eight categories of depressive disorders listed in the *DSM*-5.

## Disruptive Mood Dysregulation Disorder

This diagnosis is new. It was created to reduce the risk of overdiagnosis and treatment of bipolar disorder in children (APA, 2013a). The diagnosis is available for children from six to eighteen years of age.

The core feature of disruptive mood dysregulation disorder is chronic, severe, persistent irritability (APA). This irritability has two prominent clinical manifestations, the first of which is frequent temper outbursts. These outbursts typically occur in response to frustration and can be

verbal or behavioral (behavioral outburst take the form of aggression against property, self, or others). Outbursts must occur frequently (i.e., on average, three or more times per week) over at least one year in at least two settings such as in the home and at school. Outbursts must be developmentally inappropriate. The second manifestation of severe irritability consists of a chronic, persistently irritable or angry mood that is present between outbursts. This irritable or angry mood must be characteristic of the child, being present most of the day, nearly every day, and noticeable by others in the child's environment (APA).

The clinical presentation of disruptive mood dysregulation disorder must be carefully distinguished from presentations of other related conditions, particularly pediatric bipolar disorder (APA, 2013a). Disruptive mood dysregulation disorder was added to *DSM-5* to address the considerable concern about the appropriate classification and treatment of children who present with chronic, persistent irritability relative to children who present with classic (i.e., episodic) bipolar disorder. In the *DSM-5*, the term bipolar disorder is explicitly reserved for episodic presentations of bipolar symptoms.

# Major Depressive Disorder

Major depressive disorder is characterized by a period of at least two weeks during which the youth experiences sadness, hopelessness, guilt, loss of interest in activities that are usually enjoyable, and/or irritability most of the time. Along with either a depressed or irritable mood or a loss of interest in previously pleasurable activities, youth diagnosed with major depressive disorder must experience at least four of the following:

- Significant change in weight (or failure to meet expected weight gain)
- Sleep disturbance
- Series of unintentional or purposeless motions (psychomotor agitation) or a visible slowing down of speech or other movements or reactions (psychomotor retardation)
- Fatigue or loss of energy most of the time
- Excessive feelings of worthlessness or guilt
- Difficulty thinking or concentrating
- Recurrent thoughts of death or suicide (APA, 2013a)

It is important to note that the youth's mood must differ from their usual mood and cannot be attributable to bereavement, a general medical condition, and/or substance abuse, although those conditions may co-occur and even contribute to depression. For major depressive disorder to be present, symptoms must be exhibited nearly every day and the depressed mood must last most of the day. Insomnia or fatigue is often the first noticeable and complained of symptom (APA).

# Persistent Depressive Disorder (Dysthymia)

Persistent depressive disorder (dysthymia) is a depressive disorder in which the symptoms are chronic and persistent but less severe than major depressive disorder (APA & AACAP, n.d.). The disorder occurs when youth experience a sustained depressed mood for most of the day, for more days than not, for at least one year (compared to two years for adults). Symptom-free intervals last no longer than two consecutive months. The youth must experience a depressed mood and have at least two of the following symptoms:

- Altered appetite (eating too much or too little)
- Sleep disturbance (sleeping too much or too little)
- Fatigue or loss of energy
- Low self-esteem
- Difficult thinking or concentrating
- Sense of hopelessness (APA, 2013a)

Because persistent depressive disorder (dysthymia) is a chronic disorder, youth often consider their symptoms a part of who they are and do not report them unless asked directly. Persistent depressive disorder (dysthymia) should not be diagnosed if the child or adolescent has ever experienced mania or if the onset of depressed mood meet criteria for major depressive disorder.

# Premenstrual Dysphoric Disorder

Premenstrual dysphoric disorder was previously included in the appendices of the *DSM-IV-TR*. However, this disorder is now officially a part of the depressive disorders section in *DSM-5*. The decision to move premenstrual dysphoric disorder to the main body of *DSM-5* was based on evidence that two to five percent of menstruating women experience a unique depressive disorder that begins following ovulation, remits within several days of menses, and leads to significant interference in daily life (Gotlib & LeMoult, 2014).

A diagnosis of premenstrual dysphoric disorder requires that at least five clinically significant symptoms occur repeatedly during the premenstrual phase of the cycle, and that these symptoms remit at or shortly after the onset of menses (APA, 2013a). At least one symptom must reflect disturbance in general mood: mood lability, irritability, dysphoria, or anxiety. In addition, individuals must endorse at least one of the following physical/behavioral symptoms:

- Anhedonia
- Difficulty concentrating
- Lethargy
- Appetite changes
- Sleep changes
- Overwhelmed feelings
- Physical symptoms.

These symptoms must have occurred in most of the menstrual cycles during the past year and must be severe enough to cause marked impairment in work or social functioning (APA).

# Substance/Medication Induced Depressive Disorder

According to the APA, the diagnostic features of substance/medication-induced depressive disorder include the symptoms of a depressive disorder, such as major depressive disorder; however, the depressive symptoms are associated with the ingestion, injection, or inhalation of a substance (e.g., drug of abuse, toxin, psychotropic medication, other medication), and the depressive symptoms persist beyond the expected length of physiological effects, intoxication, or withdrawal period (2013a). As evidenced by clinical history, physical examination, or laboratory findings, the relevant depressive disorder should have developed during or within one month of

the use of a substance that is capable of producing the depressive disorder. Moreover, the diagnosis is not better explained by an independent depressive disorder.

Clinical judgment is essential to determine whether the substance or medication induced the depressive disorder or whether a primary depressive disorder happened to have its onset while the person was taking the substance or medication (APA, 2013a). Depressive symptoms are predominant in the clinical picture and develop during or soon after ingestion, injection, or inhalation of a substance (e.g. drug of abuse, toxin, psychotropic medication, and other medications) and the symptoms persist beyond the expected length of physiological effects, intoxication, or withdrawal period. This diagnosis should be made instead of a diagnosis of substance intoxication or substance withdrawal only when the symptoms (depressive) are sufficiently severe to warrant clinical attention. Depressive symptoms can occur in association with intoxication from alcohol, cannabis, phencyclidine, other hallucinogens, inhalants, stimulants (including cocaine), opioids, and other substances.

# Depressive Disorder Due to Another Medical Condition

Depressed disorder due to another medical condition occurs when there is evidence from history, physical examination, or laboratory findings that the disturbance is the direct pathophysiological consequence of another medical condition (Patricelli, n.d.). It must be established that the depressive symptoms can be etiologically related to the medical condition through a physiological mechanism before making a judgment that this is the best explanation for the symptoms of a specific individual. The presence of a clear association between the onset, exacerbation, or remission of the medical condition and the depressive symptoms is helpful in making this diagnosis. Numerous medical conditions are known to include depression as a symptomatic manifestation, including endocrine disease (e.g., hypothyroidism, Cushing's disease), cardiovascular disorders (e.g., stroke), metabolic disturbances (e.g., vitamin B12 deficiency, folate deficiency, iron deficiency), and neurological illness (e.g., Huntington's disease, Parkinson's disease, traumatic brain injury) (Patricelli).

#### Other Specified Depressive Disorder

This category applies to presentations in which symptoms characteristic of a depressive disorder that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate but do not meet the full criteria for any of the disorders in the depressive disorders diagnostic class. The other specified depressive disorder category is used in situations in which the clinician chooses to communicate the specific reason that the presentation does not meet the criteria for any specific depressive disorder. This is done by recording "other specified depressive disorder" followed by the specific reason (e.g., "short-duration depressive episode").

# **Unspecified Depressive Disorder**

This category applies to presentations in which symptoms characteristic of a depressive disorder that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate but do not meet the full criteria for any of the disorders in the depressive disorders diagnostic class (APA, 2013a). The unspecified depressive disorder

category is used in situations in which the clinician chooses not to specify the reason that the criteria are not met for a specific depressive disorder. It includes presentations for which there is insufficient information to make a more specific diagnosis (e.g., in emergency room settings).

# **Age-Specific Symptoms of Depressive Disorders**

The behavior of depressed youth may differ by age. These age-related symptoms are discussed in the following paragraphs.

#### Preschool Children

In recent years, researchers have found evidence that depression occurs in children as young as three years of age (Luby et al., 2009; Luby et al., 2003). Preschoolers with depression, compared to preschoolers who are disruptive, have significantly more sleep problems, feelings of guilt, changes in weight, diminished interest in activities that they previously enjoyed, and difficulty concentrating or thinking clearly (Luby et al., 2009). Additionally, children age three to five may be more accident-prone and have certain phobias (Harvard Mental Health Letter, 2002).

# School-aged Children and Adolescents

It is not uncommon for school-aged children and adolescents to experience depression (Klein, Torpey, & Bufferd, 2008). As a result, these youth frequently have impaired functioning at home, at school, and with friends (Klein, Torpey, & Bufferd). Children aged six to nine may be more aggressive, complain of physical problems of unknown origin, or cling to their parents and avoid new events and people (Harvard Mental Health Letter, 2002). As children enter adolescence, their symptoms may evolve into more typical adult symptoms, such as feelings of hopelessness, worry, and guilt (Harvard Mental Health Letter). It is interesting to note, however, that school-aged children experience less hopelessness, fewer incidents of sleep disturbance, fewer appetite changes, and fewer problems with motivation than do adolescents and adults (Klein, Torpey, & Bufferd).

Adolescents with depression tend to sleep more, have more appetite problems, and exhibit an irritable mood. Some experience suicidal ideation, and/or attempt suicide (Roberts, 2015). Depression may first appear at any age, but the odds increase as the child reaches puberty (APA, 2013a). Depression onset seems to peak during an individual's 20s and onset is certainly is not restricted to the teenage years (APA).

#### **Prevalence**

Depression is prevalent in adolescents. It is estimated that between 15 and 20 percent of all youth experience depression by the age of 18 (Klein, Torpey, & Bufferd, 2008). One review estimated that as many as 24 percent of adolescents experience at least one clinically significant depressive episode before the age of 18 (Roberts, 2015). The National Institute of Mental Health in America reported over 11 percent of 13 to 17 year olds reported depression leading to social problems, interruptions in academic areas, and interference with cognitive functioning (Roberts).

The National Institute of Mental Health (NIMH) cites the *National Comorbidity Survey* – *Adolescent Supplement (NCS-A)*, which calculates the prevalence of major depressive disorder and dysthymic disorder in youth (NIMH, 2010). These results are highlighted below.

Depressive Disorders Affecting 13 to 18 year olds

Some depressive disorder at some point	11.2%
Seriously debilitating depressive disorder	3.3%

#### Prevalence by Age Range

13 to 14 year olds	7.4%
15 to 16 year olds	12.2%
17 to 18 year olds	15.4%

#### Lifetime Prevalence by Gender

Females	15.0%
Males	7.5%

#### **Causes and Risk Factors**

According to the U.S. Department of Health and Human Services (1999), the exact causes of depressive disorders are not known. There is evidence, however, that genetics (specific genes passed from one generation to the next) contributes to a child's vulnerability to a depressive disorder. School-aged children and adolescents having family members who are depressed are more likely to experience depression themselves, although this does not appear to be the case for preschoolers (Klein, Torpey, & Bufferd, 2008).

Other contributing factors are environment (the conditions in which the child is growing up) and biology (neurotransmitters, hormones, and brain structure) (Klein, Torpey, & Bufferd, 2008). There is no research that shows whether family history and childhood onset of depression stems from genetic factors or whether depressed parents create an environment that increases the likelihood of a child's developing a depressive disorder (U.S. Department of Health and Human Services, 1999; Klein, Torpey, & Bufferd).

While not a risk factor, one study of children at ages three and six found that a diagnosis of an anxiety disorder at one age was likely to result in a diagnosis of depression at the other (Bufferd et al., 2012). More children in the study were diagnosed with depression at age six than at age three, but this may have been due to the children's increasing ability to verbalize their distress. Additionally, the children may have increased levels of depression due to the stress of school performance and peer comparison (Bufferd, et al.). The researchers compared this information to studies involving school-age children, adolescents, and adults and found consistent data (Bufferd, et al.). Although the study had several limitations, clinicians may find screening for both anxiety and depression fruitful if a child presents symptoms of one (Bufferd, et al.).

Depression in adults is studied more often than depression in children. Research on adults has pointed to a link between depression and serotonin and norepinephrine neurotransmitters, but

this research has not been fully supported in children and adolescents (Klein, Torpey, & Bufferd, 2008). Research on adults with and without depression has also revealed differences in production levels of the hormone cortisol, which is often associated with stress. This finding is only partially supported in children and adolescents (Klein, Torpey, & Bufferd). Depressed children and adolescents, however, are similar to depressed adults in that, like adults, they have an abnormal production of growth hormone (Klein, Torpey, & Bufferd). According to research compiled by NIMH, during childhood (pre-puberty), both males and females are equally at risk for depressive disorders (2000). However, during adolescence and continuing through adulthood, females are twice as likely as males to experience depression (Roberts, 2015; NIMH). Explanations for this significant gender difference include differences in temperament and emotional regulation, negative cognitive style and ruminative coping, relationship dependence and affiliation, biological/hormonal changes in puberty, and genetic depressive vulnerability (Roberts).

According to Roberts (2015) somatic and psychological symptoms of depression are believed to relate to biological dysfunctions in the hypothalamic-pituitary-adrenal axis (HPA) leading to sympathetic nervous system problems. Dysregulation in this area of the brain is believed to play a role in emotion regulation and feelings such as guilt and hopefulness.

Disruptive mood dysregulation disorder often presents in children with a vast history of protracted irritability (APA, 2013a). These children are often diagnosed first with oppositional defiant disorder (ODD), attention-deficit/hyperactivity disorder (ADHD), or anxiety disorders (APA). These children may also be distinguished from children at risk for bipolar disorder by examining their familial risk (APA).

#### Assessment

Proper assessment of depressive disorders in children and adolescents is essential for accurate diagnosis, effective treatment formulation, and treatment monitoring (Rudolph & Lambert, 2007). According to the AACAP, clinicians may employ various approaches in making a diagnosis (1998). Assessment of depression in children and adolescents should include information obtained directly from the child, as well as from the child's parents and teachers. Information about symptom severity, frequency, and resulting impairment can be gathered through the use of structured or semi-structured clinical interviews, self-report questionnaires, observer questionnaires, and behavioral observation (Klein, Torpey, & Bufferd, 2008). Regardless of the method of assessment, clinicians should make the diagnosis only after other causes of the child's condition are ruled out (e.g., general medical conditions, substance use, and other psychiatric disorders) (APA, 2000). The child must then meet the diagnostic criteria set forth in the *DSM-5* (APA, 2013a).

Depression assessment instruments are valuable tools in the treatment of children and adolescents. Standardized instruments can greatly improve the assessment process (Huberty, 2012; Gray et al., 2009). Rudolph and Lambert (2007) identified the Schedule for Affective Disorders and Schizophrenia (K-SADS) (Kaufman et al., 1996) as an excellent measure-based diagnostic interview for youth ages six to 18. The Children's Depression Inventory (CDI-2) is a self-report measure that is appropriate for youth between seven and 17 years of age (Kovacs, as cited by Huberty). Overall, the reliability, validity, and clinical utility of the CDI-2 is strong, but

should not be used as the sole source of information for diagnostic purposes (Huberty; Rudolph & Lambert, 2007). The Preschool Feelings Checklist (Luby et al., 2004) and the McAuther Health Behavior Questionnaire (HBQ) (Essex et al., 2002) are two questionnaires designed specifically for use with preschool children. Research indicates that both are good measures of depressive disorders in very young children (Rudolph & Lambert).

Along with assessment tools, observation may be quite helpful in diagnosing depression. Measuring non-verbal behavior in children and adolescents is most strongly associated with a depression diagnosis, and it best predicts its severity (Cusin et al., 2010).

The *DSM-5* states that clinicians should consider disruptive mood dysregulation disorder prior to potentially overdiagnosing or overtreating pediatric bipolar disorder (APA, 2013a). Severe and persistent irritability and frequent outbursts of temper occurring together should trigger consideration of disruptive mood dysregulation disorder (APA). However, it must be noted that suicidal ideation, suicide attempts, severe aggression, and psychiatric hospitalization are common in both disruptive mood dysregulation disorder and pediatric bipolar disorder.

A major concern regarding children with depression is the increased risk for suicidal ideation and possible suicide attempts. Not all children who are depressed will attempt suicide, however, and not all children who attempt suicide meet diagnostic criteria for depressive disorders. However, based on responses to assessment instruments, the clinician may wish to pursue a lethality assessment (Huberty, 2012).

# Comorbidity

Research from various sources indicate that 40 to 90 percent of youth with major depressive disorder have at least one other psychiatric disorder (AACAP, 1998). The most commonly cooccurring disorders are persistent depressive disorder (dysthymia), anxiety disorders, disruptive disorders, and substance abuse disorders (AACAP). The *DSM-5* also notes that depression is often comorbid with panic disorder, obsessive-compulsive disorder, eating disorders like anorexia nervosa and bulimia nervosa, and borderline personality disorder (APA, 2013a). Depression is more likely to begin after the onset of the comorbid disorder, with the exception of substance abuse, which tends to occur after the onset of depression (AACAP). Disruptive mood dysregulation disorder is very often comorbid with oppositional defiance disorder (ODD), and frequently occurs with other disorders as well, including behavior, mood, anxiety, and autism spectrum disorder diagnoses (APA). However, if a child meets the diagnostic criteria for either ODD or intermittent explosive disorder (IED) along with the criteria for disruptive mood dysregulation disorder, the clinician should only diagnose disruptive mood dysregulation disorder (APA).

#### **Treatments**

This section will focus on treatments for the most commonly diagnosed forms of depression among children adolescents: major depressive disorder and persistent depressive disorder (dysthymia). Disruptive mood dysregulation disorder is a new diagnosis in the *DSM-5*. At least one clinical trial to determine effective treatment for the disorder has begun, but the treatment

path is not as fully defined as those for major depressive disorder and persistent depressive disorder (dysthymia).

Analysis conducted by Burns, Hoagwood, & Mrazek (1999) indicates that evidence-based treatments for major depressive disorder and persistent depressive disorder (dysthymia) are well-established for both psychosocial and pharmacological interventions. Research has shown a combination of the two treatments offers maximum therapeutic benefits. Because youth who experience the onset of depressive disorders at a younger age typically have a worse prognosis, early intervention is crucial in treatment (Brown, 1996). Early clinical intervention is critical to prevent additional functional breakdown, relapse, and suicidal behavior (Burns, Hoagwood & Mrazek).

#### **Psychosocial Treatments**

The NIMH (2000) asserts that treating depressive disorders in children and adolescents often involves short-term psychotherapy and/or medication and targeted interventions addressing the home or school environment.

The evidence-based psychological treatments for depressive disorders are cognitive behavioral therapy (CBT) and interpersonal therapy (IPT) (Roberts, 2015; David-Ferdon & Kaslow, 2008). Psychodynamic therapy may gain popularity as a treatment protocol, as one study showed similar quality outcomes to CBT (Thoma et al., 2012). In their review of treatments for youth with depression, David-Ferdon and Kaslow reported that treatments that adhere to a treatment manual and were standardized led to greater gains than treatments that were not standardized (2008). The research also indicates that treatment gains were realized, regardless of where the treatment was provided (school, community clinics, primary care clinics, hospitals, or research settings) (David-Ferdon & Kaslow).

For this review, treatments are divided into two groups: What Works and What Seems to Work. Table 1 outlines psychosocial interventions for children and Table 2 lists those for adolescents.

#### Pharmacological Treatments

Currently, only one pharmacological treatment has been approved for use with youth with depressive disorders by the Food and Drug Administration (FDA) (Treatment for Adolescents with Depression Study [TADS], 2004). This medication, fluoxetine (a selective serotonin reuptake inhibitor [SSRI]), has been approved by the FDA for treating children eight years of age or older (Roberts; 2015; APA & AACAP, n.d.). More research has been completed on fluoxetine than any other SSRI (Roberts).

Table 1
Summary of Treatments for Children with Depression

What Works	
Stark's cognitive behavioral therapy (CBT) - child-only group or child group plus parent component	Stark's CBT includes mood monitoring, mood education, increasing positive activities and positive self-statements, and problem solving.
Fluoxetine (SSRI) in combination with CBT	Fluoxetine is the only antidepressant approved by the FDA for use in children (eight years old or older). For moderate to severe depression, pharmacological treatment in combination with psychosocial therapy may be warranted. However, because SSRIs can increase suicidal behavior in youth, children taking fluoxetine must be closely monitored by a mental health professional.
What Seems to Work	
Penn prevention program (PPP)	PPP is a CBT-based program that targets pre-adolescents and early adolescents who are at-risk for depression.
Self-control therapy	Self-control therapy is a school-based CBT that focuses on self-monitoring, self-evaluating, and causal attributions.
Behavioral therapy	Behavioral therapy includes pleasant activity monitoring, social skills training, and relaxation.

Sources: David-Ferdon & Kaslow, 2008; Weisz, 2004.

A large, multisite study with important implications, TADS examined the effectiveness of fluoxetine alone, CBT alone, a combined treatment of fluoxetine and CBT, and a placebo. Study results indicated that a combined SSRI and CBT treatment approach is superior to SSRI or CBT treatment alone and better than placebo (TADS). Additionally, the SSRI treatment and the CBT treatment were equally effective in reducing depressive symptoms, and both were better than the placebo (TADS). This study further indicated that the use of tricyclic antidepressants for the treatment of youth with major depressive disorder is not supported (TADS). Additional studies have found that the lack of significant treatment effect and the presence of problematic side effects of tricyclic antidepressants indicate that they do not work with adolescents (Roberts, 2015).

#### Risk of Suicidal Behavior

The U.S. Department of Health and Human Services (1999) asserts that depressive disorders dramatically increase the risk of suicide. Accordingly, the potential for suicidal behavior is a grave matter and clinicians providing treatment must take it into account. One study found that depressed adolescents were five times more likely than adolescents without depression to attempt suicide (U.S. Department of Health and Human Services).

Table 2 Summary of Treatments for Adolescents with Depression

What Works		
Cognitive behavioral therapy (CBT) provided in a group setting	CBT for depression focuses on identifying thought and behavioral patterns that lead to or maintain the problematic symptoms.	
Interpersonal therapy (IPT) provided individually	In IPT, the therapist and patient address the patient's interpersonal communication skills, interpersonal conflicts, and family relationship problems.	
Fluoxetine (SSRI) in combination with CBT	Fluoxetine is the only antidepressant approved by the FDA for use in children (eight years old or older). For moderate to severe depression, pharmacological treatment in combination with psychosocial therapy may be warranted. However, because SSRIs can increase suicidal behavior in youth, children taking fluoxetine must be closely monitored by a mental health professional.	
What Seems to Work		
CBT in a group or individual setting with a parent/family component	CBT for depression focuses on identifying thought and behavioral patterns that lead to or maintain the problematic symptoms.	
Adolecent coping with depression (CWD-A)	CWD-A includes practicing relaxation and addressing maladaptive patterns in thinking, as well as scheduling pleasant activities, and learning communication and conflict resolution skills.	
Interpersonal psychotherapy for depressed adolescents (IPT-A)	IPT-A addresses the adolescent's specific interpersonal relationships and conflicts, and helps the adolescent be more effective in their relationships with others.	
Physical exercise	Physical exercise has shown promise in improving symptoms of depression in adolescents. Group-based and supervised light- or moderate-intensity exercise activities 3 times a week for a period of between 6 to 11 or 12 weeks may bring about an improvement in depression. Additional research is need.	
Not Adequately Tested		
Dietary supplements	Supplements such as St. John's Wort, SAM-e, and Omega-3 have not been adequately tested and may have harmful side effects or interact with other medications. Parents should discuss supplement use with a mental health care professional.	
What Does Not Work		
Tricyclic antidepressants	These antidepressants can have problematic side effects and are not recommended for children or adolescents with depression.	

Source: Carter et al., 2016; Roberts, 2015; David-Ferdon & Kaslow, 2008.

There has been considerable debate about the use of antidepressants to treat youth with depression, specifically whether their use increases the risk of suicidal behaviors. U.S. manufacturers are now required by the FDA to place a "black box" warning label on antidepressant medications prescribed for youth. A more detailed discussion of the use of antidepressants to treat children and adolescents is provided in the "Antidepressants and the Risk of Suicidal Behavior" section of the *Collection*.

#### **Unproven Treatments**

Several treatments have been found to be ineffective in treating depression. Evidence indicates that tricyclic antidepressants are not efficacious (Klein, Dougherty, & Olino, 2005). The National Depressive and Manic-Depressive Association (2001) recognizes that various alternative treatments may positively affect depressive disorders, but asserts that such treatments ought not to be endorsed. The Association asserts there is no scientific data supporting the use of dietary supplements such as Omega-3, St. John's Wort, or SAM-e; in fact, they may have harmful side effects. Accordingly, parents should discuss their use with the clinician.

#### **Cultural Considerations**

As indicated by Yaylayan (2002), culture can influence how children communicate symptoms of depressive disorders. Complaints of nervousness and headaches are more common among Latino and Mediterranean cultures. Complaints of weakness or weariness are more prevalent among the Asian culture. According to Bender, there is no ethnic majority in the population of depressed children under the age of eight (2013). Minority children often have somatic complaints or are angry when they are depressed or anxious, and Asian children are often more emotionally reactive than their white counterparts (AACAP, 2013a). It is important that clinicians are aware of the youth's cultural background as well as the norms of their culture.

More research is being conducted on the impact of culture on the assessment and treatment of depressive disorders. As noted by Kaslow & Thompson (1998), there is a noticeable deficit of cultural information about treating depressive disorders in children and adolescents. Table 3 outlines some somatic (relating to, or affecting, the body) expressions that may signal depressive symptoms by culture.

There is great variability in the incidence of major depressive disorder diagnosis among different cultures. Additionally, there are culturally distinct ways that individuals express a distressing experience (Jenkins, Kleinman, & Good, 2001). In some cultures, people feel emotions introspectively. In others, people feel emotions within personal relationships or within events and situations (Jenkins, Kleinman, & Good). Some cultures may not permit members to express certain emotions, and these permissions may be further regulated by an individual's class or status within the culture (Jenkins, Kleinman, & Good).

The *DSM-5* warns against linking cultures to the likelihood of symptoms (APA, 2013a). Instead, clinicians should recognize that primary care practitioners often miss depressive symptoms when they occur as somatic symptoms (APA). Insomnia and loss of energy are the most-frequent complaints (APA).

Table 3
Somatic Expressions Signaling Depressive Symptoms

Country or Culture	Expression	
India	Sinking heart; feeling hot; gas	
Nigeria	Heat in the head; biting sensation all over the body; heaviness sensation in the head	
Mexican Americans	Nervi's; brain ache; "brain exploding"	
Chinese	Neurasthenia	
Dubai	"My chest feels tight"; "I am tired, fatigued"; broken body	
United Arab Emirates	"The heart is poisoning me"; "as if there is hot water over my back"; "something is blocking my throat"	

Source: Ahmed & Bhugra, 2007.

#### **Overview for Families**

There are three major types of depressive disorders that impact children and adolescents. Families may look for some or all of these symptoms if they suspect their child suffers from a depressive disorder.

# Major Depressive Disorder

For a child or adolescent to have major depressive disorder, the following symptoms must be present:

- A time of two weeks or more with some of the following symptoms:
  - Sadness
  - Hopelessness
  - Guilt
  - Loss of interest in activities that are usually enjoyable
  - Irritability most of the time
- Additionally, the child must experience at least four of the following:
  - Significant change in weight (or failure to meet expected weight gain)
  - Sleep disturbance
  - Series of unintentional or purposeless motions (psychomotor agitation)
  - Fatigue or loss of energy most of the time
  - Excessive feelings of worthlessness or guilt
  - Difficulty thinking or concentrating
  - Recurrent thoughts of death or suicide

The child's mood must be different from his or her usual mood, and it cannot be tied to mourning the loss of a loved one, a general medical condition, and/or substance abuse. The mood

and symptoms must be present nearly every day, and the depressed mood must last for most of the day (APA, 2013a). Often, the family first notices or the child first complains of insomnia or fatigue (APA).

Other symptoms families should be aware of include:

- Feeling persistently sad or blue
- Talking about suicide or being better off dead
- Becoming suddenly much more irritable
- Having a marked deterioration in school or home functioning
- Reporting persistent physical complaints and/or making many visits to school nurses
- Failing to engage in previously pleasurable activities or interactions with friends
- Abusing substances

# Persistent Depressive Disorder (Dysthymia)

Symptoms of persistent depressive disorder (dysthymia) are less severe than major depressive disorder but tend to last longer. The child experiences a persistent depressed mood for most of the day, for more days than not, for at least one year. The symptoms cannot stop for more than two consecutive months. The youth must experience a depressed mood and have at least two of the following symptoms:

- Altered appetite (eating too much or too little)
- Sleep disturbance (sleeping too much or too little)
- Fatigue or loss of energy
- Low self-esteem
- Difficult thinking or concentrating
- Sense of hopelessness

Because persistent depressive disorder (dysthymia) is a chronic disorder, youth often consider symptoms a part of who they are and do not report them unless asked directly.

Persistent depressive disorder (dysthymia) should not be diagnosed if the child or adolescent has ever experienced mania or if the onset of depressed mood meets criteria for major depressive disorder.

#### Disruptive Mood Dysregulation Disorder

Disruptive mood dysregulation disorder is a childhood condition of extreme irritability, anger, and frequent, intense temper outbursts. Diagnosis requires:

- Severe temper outbursts at least three times per week;
- Sad, irritable, or angry mood almost daily;
- The child's reaction is bigger than expected;
- The child must be at least six years of age with symptoms beginning before age ten;
- Symptoms are present for at least one year; and
- The child has trouble functioning in more than one place (AACAP, 2013b).

These symptoms should occur in two of the three environments:

- At school,
- At home, and/or
- With peers, and the symptoms must be severe in at least one of the settings.

A child with disruptive mood dysregulation disorder usually has a history of chronic irritability before he or she meets the diagnostic criteria (APA, 2013a). Doctors may have diagnosed the frustration as oppositional defiant disorder in the past (APA). Children with disruptive mood dysregulation disorder often struggle in school and during extracurricular activities because of their recurrent frustration (APA). Their relationships with both family and friends are also severely impacted (APA).

# **Resources and Organizations**

#### American Academy of Child & Adolescent Psychiatry, Depression Resource Center

http://www.aacap.org/AACAP/Families\_and\_Youth/Resource\_Centers/Depression\_Resource\_Center/Home.aspx

#### **American Psychiatric Association**

https://www.psychiatry.org/

#### **American Psychological Association**

http://www.apa.org/

### **Mental Health America**

Depression in Teens

http://www.mentalhealthamerica.net/conditions/depression-teens

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# ANXIETY DISORDERS

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#### Introduction

Anxiety disorders are disorders that cause children and adolescents to feel frightened, distressed, and uneasy due to perceived threats or stressors. Although most children and adolescents experience fears and worries, which can be labeled as anxiety, the fears and worries present in anxiety disorders actually impede daily activities or functioning (Christophersen & Mortweet, 2001). The *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)* distinguishes anxiety from fear, in that fear is an emotional response to a real or perceived *imminent* threat, and anxiety is the anticipation of a *future* threat (APA, 2013a). When both anxiety and the impairment of normal activities are evident, an anxiety disorder may be present.

Problems related to fears and anxieties are relatively common in youth, with the lifetime prevalence rates of clinical problems ranging from 6 to 15 percent (Silverman & Ginsburg, 1998; U.S. Public Health Service, 2000). The prevalence of anxiety disorders in children and adolescents is higher than almost all other mental disorders (U.S. Department of Health and Human Services, 1999). Youth with anxiety problems experience significant and often lasting impairment, such as poor performance at school and work, social problems, and family conflict (Grills-Taquechel & Ollendick, 2012; Langley et al., 2004). Anxiety often occurs with other disorders, including behavioral problems, depression, and even additional anxiety disorders (Albano, Chorpita, & Barlow, 2003). Thus, the problems found in youth with anxiety disorders can be substantial (Costello, Angold, & Keeler, 1999; Pine et al., 1998).

# **Categories**

In 2013, the American Psychiatric Association released the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. The *DSM-5* no longer considers Obsessive-Compulsive Disorder (OCD) or Post-Traumatic Stress Disorder (PTSD) as anxiety disorders. These disorders will be discussed in separate sections of the *Collection*.

# Recent Changes from the DSM-IV to the DSM-5

The *DSM-5* removed several disorders from the anxiety disorders category, including OCD, PTSD, and acute stress disorder. However, the APA does note the close relationship between these disorders and anxiety disorders. One significant change is the developmental approach and examination of disorders across the lifespan, including children and older adults. Some conditions are grouped together as syndromes because the symptoms are not sufficiently distinct to separate the disorders. Others have been separated into distinct groups (Anxiety and Depression Association of America, 2013). Table 1 outlines the changes to the Anxiety Disorders classification.

Table 1

DSM-5 Changes to the Anxiety Disorders Classification

Disorder	Changes	
Panic Attack	The <i>DSM-IV</i> described several different types of panic attacks; however, the <i>DSM-5</i> limits those types to expected and unexpected. A panic attack can be a specifier or prognostic factor for severity of diagnosis and comorbidity across disorders.	
Panic Disorder and Agoraphobia	In the <i>DSM-IV</i> , the two were diagnosed together. In the DSM-5, each is a separate diagnosis with separate criteria.	
Social Anxiety Disorder (Social Phobia)	The <i>DSM-5</i> changes the "generalized" specifier to a "performance only" specifier. This notes that anxiety and avoidance can manifest only in performance situations, like public speaking in schools, and not in other non-performance social situations.	

Source: APA, 2013a.

Table 2 outlines the anxiety disorders that affect children and adolescents present in the *DSM-5* as compared to the *DSM-IV-TR*. Note the changes in PTSD, agoraphobia, panic disorder, panic attacks, and selective mutism.

Table 2
Anxiety Disorders Affecting Children & Adolescents

Disorder	DSM-IV Description	DSM-5 Description
Separation Anxiety Disorder (SAD)	A disabling and irrational fear of separation from caregivers.	A disabling and irrational fear of separation from caregivers, who may be children or adults.
Social Anxiety Disorder/ Social Phobia	A disabling and irrational fear of social encounters with non-family members.	A disabling and irrational fear of social encounters with non-family members.
Post-traumatic Stress Disorder (PTSD)	Re-experiencing, avoidance, and hyperarousal symptoms following a traumatic event.	The <i>DSM-5</i> recategorized PTSD and no longer considers it an anxiety disorder. Refer to the PTSD section of the <i>Collection</i> for more information.
Specific Phobias (SP)	A disabling and irrational fear of something that poses little or no actual danger.	A disabling and irrational fear of something that poses little or no actual danger.
Generalized Anxiety Disorder (GAD)	Chronic, exaggerated, and overwhelming worries about multiple every day, routine life events or activities.	Chronic, exaggerated, and overwhelming worries about multiple every day, routine life events or activities.
Agoraphobia	Anxiety about being in places where escape may be difficult or help may not be available in the event of a panic attack.	No longer linked with panic disorder. Must endorse fears from two or more agoraphobic situations.
Panic Disorder	Linked with agoraphobia. Chronic fears of having panic attacks after having at least one uncued panic attack.	No longer linked with agoraphobia. Chronic fears of having panic attacks after having at least one uncued panic attack.
Panic Attacks	Intense fear or discomfort for distinct timeframe without any real danger. Categories: unexpected (uncued) panic attacks, situationally bound (cued) panic attacks, and situationally predisposed panic attacks.	Intense fear or discomfort for distinct timeframe without any real danger. The <i>DSM-5</i> no longer utilizes categories of panic attacks, but instead limits the types to expected and unexpected. Panic attacks may be applied to all <i>DSM-5</i> disorders as a specifier.
Selective Mutism	Previously included in "Disorders Usually First Diagnosed in Infancy, Childhood or Adolescence." The child speaks in some locations, but not others, even when expected to speak.	Now classified as anxiety disorder, as most children affected by selective mutism are anxious. The child speaks in some locations, but not others, even when expected to speak.

Source: APA, 1994; APA, 2000; APA, 2013a.

The *DSM-5* is a manual for assessment and diagnosis of mental health disorders and does not include information for treatment of any disorder. In the future, more evidence supporting treatments of disorders with *DSM-5* classifications will be available as clinical studies using *DSM-5* criteria are conducted. As a result, the *Collection* will reference studies that utilize *DSM-IV* diagnostic criteria to explain symptoms and treatments.

# **Prevalence**

Table 3 outlines the onset age and prevalence of anxiety disorders in children and adolescents.

Table 3

Onset Age and Prevalence of Anxiety Disorders

Disorder	Onset Age	Prevalence
Separation Anxiety Disorder	As early as preschool age, through childhood, rarely adolescence	Children: 4% Adolescents: 1.6%
Selective Mutism	Usually before age 5	0.03% – 1% by setting
Specific Phobia		Children: 5% 13 – 17 year olds: 16%
Social Anxiety Disorder (Social Phobia)		Prevalence in children and adolescents are comparable to prevalence in adults
Panic Disorder	Usually after 14 years of age	Diagnosed before 14 years: < 0.4% Adolescents: 2% – 3%
Agoraphobia	May occur in childhood, but peaks in late adolescence and early adulthood	Adolescents: 1.7%
Generalized Anxiety Disorder		Adolescents: 0.9%

Source: APA, 2013a.

#### **Causes and Risk Factors**

Research has focused on the risk factors for developing an anxiety disorder in childhood (Albano, Chorpita, & Barlow, 2003; Grils-Taquechel & Ollendick, 2012). Some researchers have described a "triple vulnerability" model of anxiety development (Barlow, 2002). This model describes how three separate risk factors work together to increase the child's chance of having

an anxiety problem. The first risk factor is having some biological predisposition to anxiety; that is, some children are more likely to experience higher amounts of anxiety than others (Eaves et al., 1997; Eley et al., 2003). The second risk factor is having a psychological vulnerability related to "feeling" an uncontrollable or unpredictable threat or danger. Thus, some children may be more likely than others to perceive a situation as threatening. There are many reasons a child may perceive the world in this way, including family or other social modeling (e.g., peers). Finally, the third risk factor is having a direct experience with anxiety-provoking situations. Thus, these three risk factors combine when a child is more anxious or inhibited by nature, interprets many situations as threatening, and has already experienced anxiety-provoking situations. Such a child is considered to be at risk for developing anxiety problems.

Research also suggests that there are patterns of gender differences, depending upon the disorder. For example, more females are diagnosed with specific phobia than males (Beidel & Turner, 2005). For social anxiety disorder and generalized anxiety disorder (GAD), rates are similar in childhood but, during adolescence, female rates of diagnosis outnumber males (Beidel & Turner). Data on gender differences for SAD, post-traumatic stress disorder (PTSD), and panic disorder have been less conclusive (Beidel & Turner). In addition, stomach pain in children (called functional abdominal pain (FAP)) has been linked to anxiety disorders later in life, even if abdominal pain is resolved (Shelby et al., 2013).

Although not a risk factor, a study by Bufferd et al. (2012) found a possible correlation between anxiety and depression. A statistically significant number of study participants diagnosed with depression at three years of age were more likely to be diagnosed with either anxiety or social phobias at six years of age. The opposite also held statistical significance. Researchers compared this study to information involving school-age children, adolescents, and adults, and found consistent data (Bufferd et al.). General anxiety disorder (GAD) rates did fall from age three to age six, though the rates of most disorders were consistent across time (Bufferd et al.). The study mentions several limitations, including the short initial analysis period and a relatively homogenous sample, but clinicians may find screening both anxiety and depression beneficial if a child exhibits symptoms of one (Bufferd et al.).

## Assessment

Unless otherwise cited, the information discussed in this section is from a personal communication with Michael Southam-Gerow and Shannon E. Hourigan on May 11, 2009. Any attempt to define problematic anxiety in youth must clearly define what constitutes typical anxiety for the youth's age, environment, and development. Anxiety and fear are defined as a complex combination of three types of reactions to a perceived threat:

- 1. Overt behavioral responses (e.g., running away, closing one's eyes, or trembling voice);
- 2. Physiological responses (e.g., changes in heart or breathing rate, muscle tension, or upset stomach); and
- 3. Subjective responses (e.g., thoughts of being scared or thoughts of bodily harm).

Another important consideration in assessing anxiety disorders in youth is their development. For example, separation anxiety is a typical phenomenon for an 18-month-old child. Similarly, fear of the dark is common for children around age four. Thus, assessing anxiety in children

requires knowledge of child development. Because anxiety is a natural and normal human experience, assessment of anxiety in youth requires attention to the level of impairment that a youth experiences because of anxiety. Accordingly, intense levels of anxiety do not constitute anxiety disorders without the presence of impairment.

Assessment for anxiety disorders should include a medical history and a physical examination within the past 12 months, with special focus on conditions that may mimic anxiety disorders (American Academy of Child & Adolescent Psychiatry [AACAP], 1997). As noted by Huberty (2002), in diagnosing anxiety disorders, the provider should ensure that youth meet the appropriate diagnostic criteria. The provider must also identify those symptoms especially pertinent to children and adolescents. Structured diagnostic interviews can be extremely useful in assessing youth, particularly when administered independently to the youth and the parent. Moreover, gastrointestinal disorders occur more frequently in youth with anxiety compared to youth without anxiety. Youth with gastrointestinal symptoms also had higher levels of anxiety symptom severity (Cunningham et al., 2013). Screening for gastrointestinal disorders could help improve treatment outcomes by identifying gastrointestinal symptoms that may interfere with treatment progress. In addition, it may be beneficial for providers to assess for anxiety if a child presents with gastrological symptoms (APA, 2013b).

A thorough assessment is critical not only because there are numerous anxiety-related disorders, but also because anxiety is often comorbid with other disorders (McLeod, Jensen-Doss, & Ollendick, 2013). For instance, although PTSD is no longer classified as an anxiety disorder, anxiety may be mistaken for PTSD if a connection between the symptoms and any history of trauma is not identified. Cases in which children exhibit an inability to move past frightening or stressful situations should be evaluated for PTSD, as it is a serious and potentially debilitating disorder (Anxiety and Depression Association of America [ADAA], n.d.).

The following are two particularly effective diagnostic interviews:

- Anxiety Disorders Interview Schedule for Children (ADIS-C)
- Schedule for Affective Disorders and Schizophrenia-Children's Version (K-SADS) (Southam-Gerow & Chorpita, 2007)

Assessing anxiety may require using multiple methods to gather information in order to understand a child or adolescent's behavior across the many settings in which he or she functions (e.g., school and home). Typically, questionnaires and interviews are used to assess anxiety. Questionnaires that measure anxiety disorders include:

- Revised Children's Anxiety and Depression Scale
- Screen for Children's Anxiety and Related Disorders (SCARED)
- Spence Children's Anxiety Scale (SCAS) (Southam-Gerow & Chorpita)
- Fear Survey Schedule for Children-Revised (Ollendick, 1983)
- Beck Anxiety Inventory

The Multidimensional Anxiety Scale for Children (MASC) does not assess *DSM* disorders. All of these measures have strong psychometric profiles (Southam-Gerow & Chorpita).

# Comorbidity

Youth diagnosed with an anxiety disorder may also have other mental health disorders. Research has revealed anxiety disorders to be comorbid with attention-deficit/hyperactivity disorder (ADHD), conduct disorder (CD), depression, and dysthymia (Southam-Gerow & Chorpita, 2007). In addition, studies show that one-third of youth having one anxiety disorder meet the criteria for two or more anxiety disorders (AACAP, 1997). Furthermore, it has been found that anxiety appears to precede depression; research indicates that between 28 and 69 percent of youth with anxiety disorders have comorbid major depression (AACAP). When depression and anxiety occur together, there is a significantly higher risk for impairment (Cummings, Caporino, & Kendall, 2014).

Substance use disorder may also co-occur with anxiety disorders (Compton, Burns, & Egger, 2002; Grant et al., 2004). Some research has found that older youth may use alcohol and other substances to reduce the symptoms of anxiety (Jellinek, Patel, & Froehle, 2002). This practice is known as self-medication. Merriam-Webster defines self-medication as "medicating oneself especially without the advice of a physician" (2014). Self-medication can be extremely detrimental because the use or abuse of substances can ultimately worsen symptoms, and certain substances may actually generate symptoms of anxiety.

## **Treatments**

The treatment of anxiety disorders in youth is usually multimodal in nature. Wide-ranging treatments have been described in the literature, but only two primary treatments have been designated as evidence-based: cognitive behavioral therapy (CBT) and treatment with selective serotonin reuptake inhibitors (SSRIs) (see Ollendick & King, 2012). It is worth noting that CBT has been tested and found to be effective for anxiety disorders in youth in over 35 separate randomized trials. Treatments are outlined in Table 4.

# Psychological Treatments

The many psychological treatments available to treat youth with anxiety disorders are described in the paragraphs that follow.

## Behavioral Therapy and Cognitive Behavioral Therapy

Behavioral therapy and cognitive behavioral therapy (CBT) are the most studied and best-supported treatments for helping youth diagnosed with an anxiety disorder (Chorpita & Southam-Gerow, 2006; Silverman, Ollendick, & King, 2012; Pina & Viswesvaran, 2008). These approaches, though diverse, typically include what is called exposure therapy. Exposure treatment involves exposing youth in a graduated fashion to the non-dangerous situations that they fear, with a focus on having them learn that their anxiety will decrease over time. As an example, youth afraid of talking to peers would practice conversations numerous times until they felt less anxious about doing so. Often, exposure therapy involves using a hierarchy, or fear ladder, such that youth may be exposed to moderately stressful situations and work towards more difficult ones. This approach allows these youth to experience mastery and increases their self-confidence.

Other elements common to behavioral therapy and CBT include psychoeducation, relaxation, and cognitive skills. Psychoeducation entails teaching older youth and parents about what causes anxiety, the effects of anxiety, how to distinguish between problematic and non-problematic anxiety, and how to overcome problematic anxiety. Psychoeducation also teaches youth and parents to monitor levels of anxiety across a variety of situations. Both forms of therapies often use praise and/or rewards to encourage the youth's progress. Both also include relationship building between the therapist and the parents and children. Relaxation entails teaching youth how to relax through breathing exercises or by alternating muscle tension and release. Cognitive skills involve teaching youth how to observe and change their thinking so they can change how they feel and reduce their feelings of anxiety.

Most versions of behavioral therapy and CBT include parental involvement, with some versions involving the parents attending all sessions with their children. In these approaches, parents learn the same skills as their children. In addition, the parent is involved in the exposure therapy situations and in the maintenance of gains made following treatment.

Both behavioral therapy and CBT have been found to be helpful to youth of all ages and can be administered in individual and group settings (Chorpita & Southam-Gerow, 2006; Ollendick & King, 2012; Silverman, Pina, & Viswesvaran, 2008). They have also been delivered with good effects in schools, clinics, hospitals, daycare centers, and homes. Evidence supporting CBT has been found across a variety of racial and ethnic groups, including Caucasian, African American, Latino, Asian, and Multiethnic.

Because of long waiting lists, lack of clinical specialists, and a multitude of other reasons, only about 25 percent of all clinically anxious young people receive the help they need (Spence et al., 2011). Computer based CBT was created to combat this gap in care. Although it is in its infantile stages, Spence et al. reports no significant difference between computer based CBT treatments and in-house clinic based CBT and user feedback was, for the majority of respondents, positive (2011).

## Other Therapies with Research Support

There are several other treatments with modest levels of support. For example, educational support treatment, which involves providing support and education about anxiety to parents and youth with anxiety problems, has shown some promise in a several studies (Ollendick et al., 2009). There is also some support in one study for the use of hypnosis in youth having high levels of test-taking anxiety (Chorpita & Southam-Gerow, 2006).

# Pharmacological Treatments

Before the mid-1990s, evidence about the effectiveness of the variety of medications (e.g., tricyclic antidepressants, benzodiazepines) used to treat most childhood anxiety disorders was mixed (Bernstein & Kinlan, 1997; Coghill, 2002; Kearney & Silverman, 1998; Velosa & Riddle, 2000). Today, selective serotonin reuptake inhibitors (SSRIs) are generally the first pharmacological treatment for children with anxiety disorders. (Nutter et al., 2012). However, the FDA issued a public health advisory regarding the safety of SSRIs in children with major depressive disorder due to the risk of increased suicide attempts and suicidal ideation (Nutter et

al.). In addition, although some antidepressants are approved by the FDA for use in children, not all are (FDA, 2007). The FDA did require additional testing to be done on suicidal ideation in youth taking SSRIs in addition to an antidepressant, and at least one study showed improvement. However, the study was scrutinized for not using an untreated class in their study. An evidenced-based review of pharmacological treatments for anxiety disorders in children additionally supports the use of SSRIs as part of the treatment regimen (Strawn & McReynolds, 2012); however, the study's authors still warn of the possible increased risk in suicidal thoughts in young people using SSRIs. Finally, it should be noted that when some children take SSRIs, activation or initial worsening of symptoms occurs, but this often has little bearing on the long-term prognosis (Sullivan, 2014).

Benzodiazepines have also been shown to be effective in the treatment of anxiety disorders, but they are not a first choice treatment because they increase the risk of behavioral disinhibition in children (Nutter et al., 2012 and Strawn &McReynolds, 2012). However, for a child with panic disorders, benzodiazepines may be helpful at the beginning of a treatment path that includes SSRIs (Strawn & McReynolds). This is because benzodiazepines may control symptoms until antidepressants can take effect (Oregon State University [OSU], n.d.).

Treating a child with anxiety requires patience and persistence. Families and physicians must work together to find the proper medication and dosage. Some physicians choose to change the prescribed medication in one of two ways: by discontinuing the first and beginning the second, or by cross-tapering, a process of titrating down the old medication and increasing the new (Sullivan, 2014). Cross-tapering is only successful when the initial medication is stopped at the appropriate time. Physicians may also choose to keep the child on a combination of medications (Sullivan).

The AACAP suggests that pharmacotherapy should not be used as the sole intervention for anxiety disorders in youth. Instead, it should be used in conjunction with behavioral or psychotherapeutic treatments (1997). One large, multi-site controlled study found that, in the treatment of GAD, SAD, and social anxiety disorder, a combination of pharmacotherapy and CBT was superior to either treatment alone or a placebo (Walkup et al., 2008).

## **Unproven Treatments**

Treatments that are unproven or lack the necessary research to be called evidence-based do exist. These include, but are not limited to, play therapy, psychodynamic therapy, and the use of biofeedback. Although there is very little support for these treatments at this time, future research may later demonstrate their positive effects on youth with anxiety.

Regarding psychopharmacological interventions, there are several medications with either little evidence of efficacy or with high levels of risk. For example, there are no controlled studies evaluating the efficacy of antihistamines for anxiety disorders in youth (AACAP, 1997). The benefit of herbal remedies is also considered unproven.

Furthermore, due to the risks of impaired cognitive functioning and tardive dyskinesia (a potentially permanent involuntary movement disorder caused by the long-term use of neuroleptic drugs), neuroleptics are not recommended for treating anxiety symptoms in youth who do not

have a co-occurring diagnosis of Tourette's syndrome or psychosis (AACAP, 1997; AACAP, 2000).

Table 4
Summary of Treatments for Youth with Anxiety Disorders

What Works	
Behavioral & cognitive behavioral therapy (CBT)	Treatment that involves exposing youth to the (non-dangerous) feared stimuli and challenging the cognitions associated with the feared stimuli with the goal of the youth's learning that anxiety decreases over time
Selective serotonin reuptake inhibitors (SSRI)	Treatment with certain SSRIs have been proven to help with anxiety; however, SSRIs may increase suicidal ideation in some youth
Benzodiazepines	While proven effective, not a first choice treatment because of an increase in the risk of behavioral disinhibition
What Seems to Work	
Educational support	Psychoeducational information on anxiety provided to parents, usually in a group setting
Computer-based behavioral & cognitive behavioral therapy (CBT)	CBT administered electronically to eliminate long waiting periods or lack of clinical experts in a given area
Not Adequately Tested	
Play therapy	Therapy using self-guided play to encourage expression of feelings and healing
Antihistamines or herbs	No controlled studies on efficacy
Psychodynamic therapy	Therapy designed to uncover unconscious psychological processes to alleviate the tension thought to cause distress
Biofeedback	Minimal support for efficacy
Antipsychotics/neuroleptics	High level of risk of impaired cognitive functioning and tardive dyskinesia with long-term use; contraindicated in youth who do not also have Tourette's syndrome or psychosis

Sources: Chorpita & Southam-Gerow, 2006; Silverman, Pina, & Viswesvaran, 2008; Bernstein & Kinlan, 1997; Coghill, 2002; Kearney & Silverman, 1998; Ollendick & King, 2012; Velosa & Riddle, 2000; AACAP, 1997; AACAP 2000; Walkup et al., 2008.

# **Cultural Considerations**

*Unless otherwise cited, information in this section is taken from the DSM-5 (APA, 2013a)* 

The understanding of anxiety disorders may vary significantly from culture to culture. Studies with participants from diverse ethnic backgrounds have become more common in recent years; however, literature in the field is greatly lacking (Austin & Chorpita, 2004; Safren et al., 2000).

For instance, some studies have found differing levels of anxiety symptoms between African-American and Caucasian youth, although the differences have not been consistent across studies (Compton, Nelson, & March, 2000; Last & Perrin, 1993). The *DSM-5* states that the prevalence of anxiety disorders is greater in American Indians than non-Hispanic whites. Furthermore, non-Hispanic whites are more likely than other races (Hispanic, African American, or Asian) to be diagnosed with an anxiety disorder.

Culture and ethnicity are important considerations for the clinician assessing anxiety in youth because of how child behaviors are perceived within a cultural group. For instance, not all cultural groups use the term "anxiety." Chen, Reich, and Chung (2002) noted that, within some Asian populations, the term "anxiety" is rarely used, whereas terminology such as "being nervous" or "being tense" are more commonly used. The cultural and ethnic background of a family will also affect emotional development, and not all cultures share the same views on emotional expression and regulation (Matsumoto, 1990; Fredrickson, 1998; Friedlmeier & Trommsdorff, 1999). For example, Asians may describe symptoms of anxiety as physical complaints, since physical ailments are more acceptable. Furthermore, people of certain cultures may understand their symptoms as a defined illness known only to their culture. These preconceived notions can make diagnosis more complex.

The APA sets forth diagnosis-specific cultural considerations in the *DSM-5*. The *DSM-5* also advises clinicians to distinguish between separation anxiety disorder (SAD) and the value a culture may place on interdependence among the family. Selective mutism may be an appropriate diagnosis for a child who immigrates to a new country but refuses to speak the new language even with adequate comprehension of that new language. Non-Latino whites, African Americans and Native Americans have significantly higher rates of specific phobia than those of Asian and Latino descent.

Social anxiety disorder (social phobia) has a counterpart disorder in Asian cultures, specifically Japan and Korea, called *taijin kyofusho*, which is associated with the fear that one makes other people feel uncomfortable. It may reach delusional tendencies. Additionally, social anxiety disorder is lower in immigrants of both Latino and non-Latino white groups. Some groups may be more likely to report social anxiety but not show a prevalence of social anxiety disorder.

Panic disorders vary across cultures, and that variability may be influenced by rates of fear about mental and somatic symptoms of anxiety. Whether a panic attack is expected or unexpected may also change based on cultural expectations. In Vietnam, a panic attack in a windy environment may be associated with that wind because of *trúng gió*, meaning "hit by the wind." Latin Americans may experience *ataque de nervios* including trembling, screaming, or crying uncontrollably; aggressive or suicidal behavior; and depersonalization or derealization. This may last longer than a few minutes, and may meet the criteria of conditions other than a panic attack. In Cambodia, *khyal* attacks, or "soul loss," may accompany types of exertion. In the U.S., African Americans are significantly more functionally impaired by anxiety than non-Latino whites. Non-Latino Caribbean blacks have higher rates of objectively defined severity when diagnosed with panic disorder. However, African-American and African-Caribbean groups have lower rates of panic disorder. The *DSM-5* suggests that this may show that substantial severity and impairment is required for diagnosis in individuals of African descent. The criteria for panic

attacks vary across cultures, but cultural-specific criteria should not count as one of the four required symptoms.

Cultures also vary how they express generalized anxiety disorder (GAD). Somatic or cognitive symptoms may dominate, but the differences typically present more at the beginning of the disorder. The *DSM-5* notes that propensity for excessive worrying is not tied to a culture, although excessive worrying about a specific topic may be culturally specific. Clinicians should consider social and cultural context when evaluating whether worries are excessive by topic.

# Prevalence by Gender or Ethnicity

The *DSM-5* notes that females are two times more likely to suffer from anxiety disorders than males. There are also variations in prevalence based on the child's ethnicity. Table 5 lists the prevalence of anxiety disorders by gender and ethnicity (prevalence is for all ages of population unless specified).

There are limited studies that examine the prevalence of anxiety disorders in lesbian, gay, bisexual and transgender (LGBT) populations, but those that do point to an increased risk in anxiety in this subgroup (Institute of Medicine, 2011; Mutanski, 2011).

## **Overview for Families**

It is normal for all children to experience anxiety. Anxiety should be expected in the healthy development of a child. The difference between regular anxiety and an anxiety disorder is that an anxiety disorder is debilitating. It leaves the child unable to function in a normal, productive manner (AACAP, 2012). Most young children show fears of the dark, storms, animals, separation, or strangers. Children with an anxiety disorder often display an overly tense and sometimes agitated demeanor. Parents should not dismiss their children's anxieties and should be alert to signs of severe anxiety (AACAP). Early intervention can prevent complications (AACAP).

There are several different anxiety disorders. General symptoms of each are outlined in Table 6.

If the child's fears or anxieties are frequent, severe, and interfere with the child's life activities, the family should seek an evaluation by a qualified mental health professional or a child and adolescent psychiatrist (AACAP, 2012).

Table 5 Prevalence by Ethnicity and Gender

Disorder	Prevalence by Country or Ethnicity	Prevalence by Gender	
Separation anxiety disorder (SAD)	U.S. adults: 0.9% – 1.9% U.S. adolescents: 1.6%	For children in clinical settings, equally common in males and females	
	U.S. children: 4.0%	For children in community setting, more frequent in females	
Selective mutism	No variation in ethnicity	No variation in gender	
Specific phobia <sup>†</sup>	U.S. and Europe: 6% – 9% Asia, Africa, and Latin America: 2% – 4%	Female* to male: 2:1	
Social anxiety disorder (social phobia)	U.S.: 7%  When compared to non-Hispanic whites, higher prevalence in American Indians and lower in people of Asian, Latino, African American and Afro-Caribbean descent.  Europe: 2.3%  Worldwide: 0.5% – 2.0%	Female to male: 1.5:1 to 2.2:1	
Agoraphobia	Worldwide: 1.7%	Female to male: 2:1	
Generalized anxiety disorder	U.S.: 2.9% Other countries: 0.4% – 3.6%	Female to male: 2:1	
Panic disorder  Source: APA, 2013a.	U.S. and Europe: 2% – 3%  When compared to non-Hispanic whites, significantly higher prevalence in American Indians and significantly lower in people of Asian, Latino, African American and Afro-Caribbean descent.  Asia, Africa, and Latin America: 0.1% – 0.8%	Female to male: 2:1	

Source: APA. 2013a.
\*Females predominately experience specific phobias to animals, the natural environment, and situational concerns; both genders equally experience blood-injection-injury phobia. †Females are affected more frequently than males, beginning in childhood and peaking in adolescence at a rate of approximately 2:1.

## Table 6

## **General Symptoms of Anxiety Disorders**

## **Separation Anxiety Disorder**

- Constant thoughts and fears regarding well-being of parents and caretakers
- Refuses to go to school
- Frequent stomach aches and other physical complaints when separation from major attachment figure occurs or is anticipated
- Extreme worries about sleeping away from home
- Panic or tantrums at times of separation from parent(s) or attachment figures
- Persistent and excessive fears of being apart from major attachment figure
- Recurring separation-themed nightmares

# Social Anxiety Disorder/Social Phobia

- Extreme fear of meeting or talking to people
- Avoids social situations or has few friends
- The anxiety must occur in peer settings and not just in interactions with adults

# Post-Traumatic Stress Disorder (PTSD)

Note: PTSD is no longer listed as an anxiety disorder by the DSM-5, but is included here for informational purposes.

- Having frequent memories of the traumatic event, or, in younger children, repeating some or all of the trauma over and over in play
- Acting or feeling like the experience is happening again
- Developing physical pains when reminded of the event
- Worries about dying at a young age
- Shows more sudden and extreme emotional reactions
- Acts younger than their age

## **Specific Phobia**

- Extreme fear of a specific thing or situation (e.g. animals, needles, flying)
- Fear must cause significant distress and interfere with usual activities

## **Generalized Anxiety**

- Excessive worrying about things before they happen
- Restlessness or feeling on edge
- Sleep disturbance

continued next page

## Table 6 (Continued)

# **General Symptoms of Anxiety Disorders**

#### **Panic Disorder**

- Abrupt change from calm to anxious state reaching its peak within minutes, with symptoms including but not limited to:
  - Intense fearfulness
  - Feeling short of breath or smothered
  - Dizziness
  - Trembling or shaking
  - Fear of dying or losing control (going crazy)
  - Parathesia (numbness or tingling sensations)

# Agoraphobia

- Consistent significant fear about two (or more) of the situations listed below:
  - Using public transportation
  - Being in open spaces
  - Being in enclosed spaces
  - Standing in line or being in a crowd
  - Being outside of the home alone
- The child avoids an area or requires a companion because:
  - Fears that escape may not be easy, or
  - Fears that help might not be available if symptoms occur (includes panic or fear of incontinence).
- The fear of a situation is out of proportion to the actual danger in the situation or the sociocultural context therein.
- The fear causes clinically significant distress or impairment in functioning.
- A comorbid medical condition is present (such as a bowel disorder) due to the anxiety.
- The fear is not better explained by the symptoms of another mental disorder.

Note: Agoraphobia will be diagnosed without respect to panic disorder. If a child meets the diagnostic criteria of both disorders, both should be assigned to the child.

Sources: APA, 2013a; AACAP, 2012, 2011, 2004.

# **Resources and Organizations**

# American Academy of Child, & Adolescent Psychiatry (AACAP)

http://www.aacap.org/

Anxiety Disorders Resource Center

https://www.aacap.org/aacap/Families\_and\_Youth/Resource\_Centers/Anxiety\_Disorder\_Resource\_Center/Home.aspx

# **Anxiety and Depressive Disorders of America**

https://adaa.org/

# **Association for Behavior and Cognitive Therapies**

http://www.abct.org/Home/

## **Mental Health America**

http://www.mentalhealthamerica.net/conditions/anxiety-disorders

# **National Anxiety Foundation**

http://www.nationalanxietyfoundation.org/

## **National Institute of Mental Health (NIMH)**

https://www.nimh.nih.gov

# Social Phobia/Social Anxiety Association

http://socialphobia.org/

# Society of Clinical Child & Adolescent Psychology

https://www.clinicalchildpsychology.org/

# **Substance Abuse and Mental Health Services Administration (SAMHSA)**

https://www.samhsa.gov/

# Virginia Resources and Organizations

# **University of Virginia Health System**

Neurosciences and Behavioral Health Center

Mental Health Conditions

https://neurosciences.uvahealth.com/services/psychiatry/mental-health-conditions

**Anxiety Disorders** 

https://neurosciences.uvahealth.com/services/psychiatry/mental-health-conditions/anxiety-disorders

# Virginia Commonwealth University Medical Center

Children's Mental Health Resource Center

https://www.chrichmond.org/Children's-Mental-Health-Resource-Center.htm

## **Virginia Polytechnic Institute and State University**

Child Study Center

https://www.psyc.vt.edu/labs/csc

Psychological Services Center

http://www.psyc.vt.edu/outreach/psc

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# OBSESSIVE-COMPULSIVE AND RELATED DISORDERS

#### Introduction

Recent Changes from the DSM-IV to the DSM-5

#### Categories

Obsessive-Compulsive Disorder

Obsessive-Compulsive and Related Disorder Due to Another Medical Condition

Substance/Medication-Induced Obsessive-Compulsive and Related Disorder

**Body Dysmorphic Disorder** 

Hoarding Disorder

Trichotillomania (Hair-Pulling Disorder)

Excoriation (Skin-Picking Disorder)

#### **Prevalence**

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Psychological Factors

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**Assessment** 

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**Treatments** 

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## Introduction

Obsessive-compulsive and related disorders (OCRD) is the umbrella term that describes disorders that have several features in common, including obsessive preoccupation and repetitive behaviors. These disorders have enough similarities to group them together in the same diagnostic classification, but enough important differences to exist as distinct subtypes. Because of this, the term OCRD will be used throughout this section to discuss this group of disorders, and the specific disorder names (e.g., "obsessive-compulsive disorder" or "trichotillomania") will be used when those individual disorders are referenced. Information regarding the impact of the subtypes "obsessive-compulsive and related disorder due to another medical condition" and "substance/medication-induced obsessive-compulsive and related disorder" on youth is limited, so this section will not focus extensively on these subtypes.

Typically, OCRD are characterized by obsessions and compulsions (March & Mulle, 1998). Obsessions are persistent and intrusive thoughts, ideas, impulses, or images that result in anxiety (American Psychiatric Association [APA], 2000). Compulsions take the form of overt behavioral acts or rituals, or covert mental acts (e.g., silently counting). Compulsions may also include repetitive washing, checking, touching, counting, and ordering/arranging. Compulsive hoarding

and praying may also occur as a reaction to an obsession (March & Mulle, 1998). Compulsions function to reduce the anxiety associated with the child's or adolescent's obsessions (APA, 2013a).

OCRD have several developmental differences in children (Swedo et al., 1989). The adult with OCRD often recognizes that his or her behavior is abnormal and problematic. However, due to undeveloped cognitive abilities, children with OCRD may not understand that their behaviors are abnormal. Individuals with OCRD experience distress when their compulsions cannot be completed. In children, this distress may manifest as tantrums or angry outbursts. Furthermore, children may not be able to specify the consequence of not engaging in their compulsion and may report a vague sense that "something bad might happen" if they are not able to complete the compulsion (Barrett et al., 2008).

The impairment caused by OCRD is significant. Because compulsions serve as the primary coping mechanism, youth with OCRD who experience increased levels of distress will respond by increasing the intensity and/or magnitude of their compulsion. Thus, these youth may spend more and more time engaging in their rituals. Their dependence on their ineffective coping mechanism, in turn, interferes with school, work, and social functioning. Accordingly, youth with OCRD may be reluctant to attend school for fear of embarrassment, and they often withdraw from social activities. Youth with OCRD also possess a higher risk for comorbid anxiety disorders (e.g., social anxiety and panic disorder) and depression. While symptoms may fluctuate, the overall trend in symptom severity increases over the lifetime (APA, 2013a).

# Recent Changes from the DSM-IV-TR to the DSM-5

In 2013, the American Psychiatric Association released the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). The chapter on OCRD was created to reflect evidence of OCRD's similarities with, as well as their distinction from, other anxiety disorders (APA, 2013b). Disorders included in the OCRD section include obsessive-compulsive disorder, body dysmorphic disorder, trichotillomania (hair-pulling disorder), excoriation (skin-picking disorder), and hoarding disorder (APA, 2013b). While excoriation disorder and trichotillomania were previously classified as habit disorders, the DSM-5 re-classified these disorders as OCRD. That is because these disorders share the same characteristics of (1) preoccupations and repetitive behaviors or mental acts, or (2) body-focused repetitive behaviors with repeated attempts to stop doing them (APA, 2013a). Two new disorders were also included in the DSM-5. The first, obsessive-compulsive and related disorder due to another medical condition, was included in the DSM-5 because of evidence that suggested that symptoms are sometimes caused by another medical disorder (APA, 2013a). The second, substance/medication-induced obsessive-compulsive and related disorder, was included because symptoms sometimes develop during or soon after intoxication or withdrawal from a substance or medication. For this diagnosis to be valid, the substance or medication must be capable of causing the symptoms.

The specifier, "with poor insight," has been broadened. Individuals with obsessive compulsive disorder now fall into one of the following three categories: good or fair insight, poor insight, or absent insight/delusional. Individuals with good or fair insight understand that their obsessions and compulsions are abnormal or irrational. In contrast, individuals categorized as "absent insight/delusional" believe their obsessions and compulsions are normal or rational thoughts,

feelings, or actions. A tic specifier for obsessive-compulsive disorder has also been added, because a comorbid tic disorder can be an important factor in the diagnosis and treatment of obsessive-compulsive disorder (APA, 2013b).

A "muscle dysmorphia" specifier was added to body dysmorphic disorder. This specifier was created to be used as a clinical tool because body dysmorphia varies from other forms of body dysmorphic disorder. There are more problematic risk behaviors associated with body dysmorphia, and evidence suggests treatment methods vary from other forms of body dysmorphic disorder (Phillips, Frost, & Mataix-Cols, 2010).

The *DSM-5* is a manual for assessment and diagnosis of mental health disorders and does not include information for treatment of any disorder. In the future, more evidence supporting treatments of disorders with *DSM-5* classifications will be available as clinical studies utilizing *DSM-5* criteria are completed. As a result, this *Collection* will reference studies that utilize *DSM-IV* diagnostic criteria to explain symptoms and treatments. Because several of these disorders were categorized differently in the past, the *DSM-5* suggests that clinicians be aware of the potential correlations with anxiety disorders.

# **Categories**

The categories of OCRD outlined in the *DSM-5* are highlighted in the following section.

# **Obsessive-Compulsive Disorder**

Obsessive-compulsive disorder is characterized by elevated anxiety or distress caused by uncontrollable and intrusive thoughts (called obsessions) and repetitive, ritualistic behaviors (called compulsions) (March & Mulle, 1998; American Academy of Child Adolescent Psychiatry [AACAP], 2012). Obsessions and/or compulsions that take up a significant portion of the youth's day and that cannot be attributed to any other disorders are the hallmark of obsessive-compulsive disorder (APA, 2013a). Figure 1 details additional information about obsessions and compulsions.

## Figure 1

## **Obsessions and Compulsions**

#### Obsessions:

- Recurrent and persistent thoughts, urges, or images the youth deems intrusive and unwanted at some point in the experience. Such thoughts, urges, or images are distressing and cause anxiety.
- The youth attempts to ignore or suppress the thoughts, urges, or images, or alternatively, neutralizes them by another thought or action (e.g., a compulsion).

## Compulsions:

- Repetitive behaviors or mental acts the youth feels compelled to perform in response to an obsession.
  - Repetitive behaviors may include handwashing, ordering, and checking.
  - Mental acts may include praying, counting, and repeating words silently.
- These behaviors/actions are performed in an attempt to prevent or reduce anxiety, distress, or a feared event. Actions are excessive and may not realistically be connected to that which they aim to prevent.

Source: APA, 2013a.

# Obsessive-Compulsive and Related Disorder Due to Another Medical Condition

The symptoms caused by obsessive-compulsive and related disorder due to another medical condition are the "direct pathophysiological consequence of another medical condition" from which the youth suffers (APA, 2013a). The judgment that the symptoms are based on another condition must be based in evidence from the youth's medical history, a physical examination or laboratory results, and confirmation that the symptoms are not better explained by another mental disorder (APA). As a result, an obsessive-compulsive and related disorder due to another medical condition diagnosis requires that a medical diagnosis be present (APA). The inclusion of this disorder acknowledges that symptoms similar to primary obsessive-compulsive and related disorders can arise as a result of other medical conditions.

# Substance/Medication-Induced Obsessive-Compulsive and Related Disorder

The symptoms caused by substance/medication-induced obsessive-compulsive and related disorder can be those of any other OCRD, including obsessions, compulsions, body-focused repetitive behaviors (APA, 2013a). Symptoms develop during or soon after intoxication or withdrawal from the substance or medication. Data regarding substance/medication-induced obsessive-compulsive and related disorder is extremely limited, but it does indicate that this disorder is very rare. As such, this section of the *Collection* will focus on the more prevalent forms of OCRD.

# **Body Dysmorphic Disorder**

The *DSM-5* has classified body dysmorphic disorder as a subtype of OCRD. Body dysmorphic disorder causes affected youth to perceive deficits in their physical appearance. However, the body imperfections characterizing body dysmorphic disorder are either not observable or only slightly observable to others. A child or adolescent with body dysmorphic disorder may check the mirror, groom excessively, skin pick, and/or seek reassurance repetitively. Moreover, the child may compare his or her appearance to others (APA, 2013a). The concerns of a person with body dysmorphic disorder are not based in weight or body fat, as they are in individuals with eating disorders.

The *DSM-5* notes that repetitive behaviors or mental acts in response to preoccupations with perceived defects or flaws in physical appearance must be present for a diagnosis of body dysmorphic disorder. Additionally muscle dysmorphia was included in the *DSM-5* as a subtype of body dysmorphia. Muscle dysmorphia is a form of body dysmorphic disorder evidenced by a concern that one is too small or not muscular enough.

Males and females are equally likely to present with body dysmorphic disorder symptoms (Ahmed, Genen, & Cook, 2013). The median onset age is 15 years; however, the most common onset age is 12 to 13 years (APA, 2013a). Almost two thirds of those with body dysmorphic disorder experience onset prior to age 18. These individuals are more likely to have a gradual onset and are more likely to attempt suicide (APA). Families should be cognizant of this slow onset possibility.

# Hoarding Disorder

Hoarding disorder is characterized by:

- Ongoing difficulty discarding or parting with possessions, regardless of value;
- Perceived need to save the items; and
- Distress associated with discarding them (APA, 2013a).

Individuals with hoarding disorder accumulate and retain so many items that they congest their living area and substantially compromise the use of the retained items (APA, 2013a). Clinicians diagnosing hoarding disorder may add specifiers that further explain the type of hoarding present. These include "with excessive acquisition" for those who purchase and acquire items for which there is no space. Additionally, specifiers may designate the insight level of the affected youth, noting the degree to which the youth recognizes that his or her hoarding viewpoint and actions are problematic (APA).

Hoarding can be distinguished from collecting by analyzing how the youth views his or her possessions. Generally, collectors are proud of their possessions and experience joy in displaying and discussing them (Anxiety and Depression Association of America [ADAA], 2010). Alternatively, those who hoard are embarrassed about their possessions and feel uncomfortable when others see them (ADAA). Clutter often replaces livable space, and the owner is sad or ashamed after acquiring additional items. Debt frequently accompanies hoarding disorder (ADAA).

Hoarding disorder begins to present symptoms around 11 to 15 years of age, begins to interfere with life around the mid-20s, and causes clinically significant impairment by the mid-30s (APA, 2013a). It appears to become more severe as the affected individual ages and is frequently chronic (APA, 2013a).

## Trichotillomania

Trichotillomania involves hair pulling from some or many body parts, including the scalp. A youth may pull hair from anywhere on the body, but it is most commonly pulled from the scalp, eyebrows or eyelashes, then less commonly from other parts of the body like axillary (underarm), facial, pubic and peri-rectal regions (APA, 2013a). These sites may change over time, and the individual may pull hair throughout the day or for sustained periods within a particular day (APA). Hair pulling may continue for years. Hair loss must occur to diagnose trichotillomania, but some youth will pull individual hairs throughout an area such that hair loss is less obvious (APA). Additionally, individuals may wear hats or wigs to camouflage hair loss.

In the *DSM-IV*, trichotillomania was categorized as a habit disorder, characterized by repetitive, yet relatively stable, behaviors that seem to occur beyond the awareness of the person performing the behavior. The *DSM-5* now designates trichotillomania as an OCRD because it shares clinical features with other categories of OCRD.

Some studies suggest that there are two subtypes of pulling: automatic pulling, which occurs largely outside of the individual's awareness, and focused pulling, which is a deliberate response

to an urge, unpleasant emotion, or sensation (Woods, Piacentini, & Himle, 2007; McGuire et al., 2012). In addition to subtypes, hair pulling is often accompanied by ritual, such as choosing the right type of hair, pulling it with the root intact, or examining or manipulating the hair after pulling, including rolling it between fingers, biting, or swallowing it (APA, 2013a). Usually hair pulling only occurs when the individual is alone or around immediate family. Some individuals will pull hair from others in secret, or from rugs or dolls to satisfy their urges (APA). Youth may report triggers such as tension, anxiety, or specific cognitions like the appearance of the hair, an itch, boredom, or specific settings (McGuire et al.).

Trichotillomania onset typically begins during childhood, usually during early childhood or early adolescence (McGuire et al., 2012). Although it is not well studied, information available suggests that symptoms may increase and later decrease and that hair pulling sites do change (McGuire et al.). There is little research to show which type of hair pulling begins first, but some research suggests that adolescent girls show a marked increase in focused pulling (McGuire et al.).

## **Excoriation Disorder**

Excoriation (skin-picking) disorder is a new entry to the *DSM-5* (APA, 2013a). Excoriation is characterized by picking at one's own skin, including healthy skin, calluses, and pimples. Individuals with excoriation disorder pick at actual and perceived skin defects, leading to physical damage (APA). Most individuals use fingernails, but they may also use tweezers or pins, and they may also rub or squeeze the skin. The individual will frequently seek out a scab or other area to pick, and then examine, play with, or mouth the removed piece of skin or scab (APA). Some picking is focused, with preceding anxiety or tension and subsequent relief, while in others picking is automatic without full awareness. Most individuals engage in both focused and automatic picking (APA).

Skin picking may occur as a result of boredom or anxiety, and it may lead to a sense of gratification when successfully completed. At least some symptoms of skin picking can be common, as one study found over 60 percent of the cohort causing some skin damage not due to a medical condition (Grant et al., 2012). Only when the symptoms reach the criteria for skin picking disorder (lesions, an attempt to stop, and accompanying distress) should the symptoms require intervention (Grant et al.).

## **Prevalence**

Table 1 outlines the prevalence of OCRD in the general population.

Table 1

Prevalence of Obsessive-Compulsive and Related Disorders (OCRD)

Disorder	Prevalence in the U.S.	International Prevalence	Gender Differences
Obsessive-compulsive disorder	1.2%	1.1 – 1.8%	Males are more commonly affected than females in childhood
Body dysmorphic disorder	2.4% of youth and adults	1.7 – 1.8% of adults	Prevalence is slightly higher in females than males
Hoarding disorder	2 – 6%	2 – 6%	Mixed results in clinical and epidemiological data
Trichotillomania	1 – 2% in adolescents		10:1 females to males in adults, but children are more equally represented in both genders
Excoriation disorder	1.4% of adults		75% or more are female
Obsessive-compulsive and related disorder due to another medical condition	Unknown Unknown		Unknown
Substance/medication-induced obsessive-compulsive and related disorder	Unknown	Unknown	Unknown

Source: APA, 2013a.

## **Causes and Risk Factors**

Although obsessive-compulsive disorder, obsessive-compulsive and related disorder due to another medical condition, substance/medication-induced obsessive-compulsive and related disorder, body dysmorphic disorder, hoarding disorder, trichotillomania, and excoriation are different disorders, they have similar biological, psychological, and social risk factors. The biological risk factors of OCRD are genetic and have neurological bases. The psychological risk factors that influence whether the biological factors are activated include emotional and experiential factors. Finally, social risk factors occur in the child's social environment (e.g., family, friends, and school) and help maintain the disorder. These risk factors will be discussed in the following paragraphs.

# **Biological Risk Factors**

Numerous studies demonstrate abnormal brain functioning in individuals with OCRD (Saxena, Brody, Schawtrz, & Lewis, 1998). These studies identify over-activity in the limbic system, including the basal ganglia and cingulate gyrus, which sets the overall emotional-disposition. The basal ganglia set the body's baseline arousal and suppress regulation of motor movement. Overactivity in this area is associated with the physical sensations of anxiety, avoidance tendencies, and tics. The cingulate gyrus is associated with an individual's cognitive flexibility. Over activity in this area is associated with rigid and inflexible thinking (obsessions) and behavior patterns (compulsions). As a result, youth with abnormal functioning in these areas may be particularly susceptible to feeling intensified fear and developing rigid thought and behavior patterns.

The causes of these biological abnormalities are unclear. Neuroimaging suggests that youth affected with OCRD have disturbances in front striatal circuits that oversee the capacity for self-regulation (Marsh, Maia & Peterson, 2009). Genes may also cause or contribute to developing obsessive-compulsive disorder. Studies show between 12 and 26 percent of first-degree relatives of those with obsessive-compulsive disorder have a risk of developing it themselves (AACAP, 2012). Family members of people with pediatric obsessive-compulsive disorder are more likely to develop it than families of those whose OCRD developed later in life (AACAP). Studies of twins, however, show that genes are not the only factor that causes OCRD and cannot address whether OCRD run in families due to shared genetic risk factors, shared environmental risk factors, or both. Many cases of OCRD are sporadic – they develop in individuals with no family history of OCRD (AACAP).

Considerable research demonstrates a genetic predisposition to OCRD and tic disorders (sudden, rapid, recurrent, nonrhythmic motor movements or vocalizations; additional information on tic disorders is provided in the *Collection's* section "Motor Disorders"). Research reveals that families of an individual diagnosed with a tic disorder are also more likely to have other first-degree relatives (i.e., parent, sibling, or offspring) with a tic disorder and/or OCRD (March & Mulle, 1998; Marsh, Maia, & Peterson, 2009). There is also evidence that a subset of children with OCRD developed symptoms after an infection of Group A beta hemolytic streptococcus (i.e., strep throat) or Sydenham's chorea, a variant of rheumatic fever (AACAP, 1998). This is called pediatric autoimmune neuropsychiatric disorder associated with strep (PANDAS). It is believed that during infection, antigens react with basal ganglia tissue, leading to OCRD and/or tic symptoms (AACAP). While PANDAS is well accepted by some, there are still dissenters.

Body dysmorphic disorder is more prevalent in youth who have a first-degree relative with OCRD (APA, 2013b). Moreover, abnormal visual processing may be a potential biological cause of body dysmorphic disorder. Visual abnormalities may impair the ability to distinguish certain facial elements; a visual weakness common to those with body dysmorphic disorder compared to individuals without (Feusner et al., 2010). These exhibited patterns suggest individuals with body dysmorphic patients process facial features in pieces rather than as a whole (Ahmed, Genen, & Cook, 2013). While this research is relatively new, it may reveal more information about biological causes of body dysmorphic disorder in the future.

There is a suggested genetic link between hoarding disorder and OCRD in families. The *DSM-5* posits that as many as 50 percent of those who hoard report having a family member who hoards

(APA, 2013a). OCRD patients present significantly more hoarding behaviors than those with non-hoarding OCRD relatives (Saxena, 2007; Samuels et al., 2007). A study of OCRD genetics revealed hoarding as the strongest familial disorder, and it revealed considerable similarities in sibling pairs (Saxena; Hasler et al., 2007). About 50 percent of the variability in hoarding may be attributed to genes (APA, 2013b).

Scientists also suggest a different cerebral glucose metabolism pattern in individuals with hoarding disorder that is distinct from both healthy comparison subjects and non-hoarding OCRD patients (Saxena, 2007; Saxena et al., 2004). Non-hoarding patients had hypermetabolism in the orbitofrontal cortex, caudate nuclei, and thalamus where hoarding patients did not; instead hoarding patients had significantly lower activity in the cingulate cortex (Saxena et al., 2004). Note that these hoarding patients were considered to have OCRD with a symptom of compulsive hoarding under the *DSM-IV*, whereas the *DSM-5* acknowledges the link between hoarding disorder and OCRD but provides for a separate diagnosis (APA, 2013a).

There is also a possible genetic predisposition to trichotillomania, as scientists discovered a mutation in the Slit and Trk-like 1 (SLITRK1) gene in patients with trichotillomania that did not exist in comparison subjects (APA, 2013a; Chamberlain et al., 2007). Excoriation disorder is more frequent in individuals with OCRD or in those whose first-degree family members have OCRD (APAb, 2013).

# **Psychological Factors**

Certain symptoms are common in people who develop OCRD, especially during childhood and adolescence. These symptoms include negative emotionality, behavioral inhibition, and a higher incidence of internalizing (APA, 2013a). The specific thought and behavior patterns that youth with OCRD develop are based on learning processes and lifetime experiences. Research suggests that most individuals experience the types of intrusive thoughts that cause distress in youth with OCRD. These thoughts may originate from a traumatic experience, illness, or information from others (e.g. family, friends, news reports, etc.). However, youth with OCRD may experience shame, guilt, or fear in response to these thoughts and have difficulty dismissing them (March & Mulle, 1998). As a result of these unpleasant and/or fearful feelings, the youth attempts to escape or avoid the fear (Mowrer, 1939). Any behaviors that are associated with the reduction in fear are then reinforced, even if these behaviors do not cause the reduction in fear.

While some compulsions, such as excessive washing, are related to the obsession (e.g., fear of contracting a disease), other compulsions are not rationally related (e.g., counting in response to fears about harming others). Furthermore, because the situations that trigger fears are not easily avoided, youth with OCRD attempt to actively avoid feelings of fear by repeatedly engaging in the behaviors associated with fear reduction. The reduction in fear positively reinforces this ritualized behavior (Mowrer, 1939). Behavior patterns maintained through this type of conditioning are difficult to extinguish. These avoidance/escape patterns prevent the youth from fully experiencing the fearful situation. Therefore, the youth's fear cannot naturally depart (in a process called "extinction") (Pierce & Cheney, 2004).

## Social Factors

OCRD are not caused by parenting or other family problems. However, the way a family reacts to a youth with OCRD can affect the disorder by either increasing or decreasing anxiety. Barrett, Shortt, and Healy (2002) found that parents of children with OCRD, compared to parents of non-OCRD children, did not as frequently use problem-solving with their children, did not encourage their children's independence, and did not have as much confidence in their children's abilities. Similarly, children with OCRD were less confident in themselves, used problem-solving less, and showed less warmth with their parents than children without OCRD.

Although parenting will not cause OCRD, physical and sexual abuse or severe trauma may contribute to the likelihood of developing the disorder (APA, 2013a). For example, body dysmorphic disorder is often related to childhood neglect and abuse (APA). Additionally, symptoms may vary slightly based on cultural values and preferences (Ahmed, Genen, & Cook, 2013). Individuals suffering from hoarding disorder report stressful and traumatic life events that cause the onset or exacerbation of the disorder, but they make this report retroactively (APA). Although research links trichotillomania to genetics, as discussed above, stress can also be a contributing factor (Chamberlain et al., 2007). Stress is more commonly present in individuals with OCRD and first degree relatives of those with OCRD than the general population (APA).

#### **Assessment**

Clinicians should screen for all OCRD when a child or adolescent displays symptoms of any of the corresponding disorders. Additionally, clinicians should be aware of the overlaps among the conditions, as well as the differences in diagnostic criteria and future treatment options during this assessment (APA, 2013a).

# **Obsessive-Compulsive Disorder**

Pediatric onset obsessive-compulsive disorder is often preceded or accompanied by sensory phenomena, including physical sensations, perceptions of what is "just right," and the need for accuracy or things to be "just right" (AACAP, 2012). Assessment of obsessive-compulsive disorder should follow general diagnostic practices, including obtaining complete developmental, medical, and family histories; evaluation of psychosocial functioning across multiple domains (e.g., family, friends, school, and home); and history of current and past symptoms (AACAP, 1998). Both the parents and the child should complete diagnostic interviews to determine mental rituals and/or obsessions that the parent might not be aware of and behavior problems that the youth may be reluctant to report.

The first challenge in diagnosing a child with obsessive-compulsive disorder is distinguishing developmentally appropriate beliefs and behaviors from those symptomatic of obsessive-compulsive disorder. For example, youth with obsessive-compulsive disorder may fear that, by merely thinking a thought (e.g., hurting a loved one), they will cause it to happen (i.e., thought-action fusion). In children, it is important to differentiate developmentally normal magical thinking from pathological beliefs that drive compulsions and cause distress (Shafran, 2001). Young children may insist on sameness and order or adhere to rigid routines, such as elaborate bedtime rituals, as part of normal development in early childhood, reflecting the need for mastery

and control (March & Mulle, 1998). Research suggests that compulsive-like behaviors are particularly common among children between the ages of two and four (Evans et al., 1997). Normal obsessive-compulsive behaviors can be differentiated from obsessive-compulsive disorder based on timing, content, and severity of the symptoms.

The role of the family and school in maintaining the obsessive-compulsive symptoms must also be assessed. Parents and family often become entangled in the youth's symptoms by making accommodations for, or even participating in, obsessive-compulsive behaviors (AACAP, 1998; Barrett, Healy-Ferrell, & March, 2004). The degree to which this occurs influences the degree of intervention in these settings. (AACAP, 2012; Hudziak et al., 2008).

Structured diagnostic interviews can help identify the presence of obsessive-compulsive disorder as well as other potential comorbid conditions. A thorough assessment will also determine the presence, age of onset, duration, and severity of each symptom. This also aids in the conceptualization and formation of a treatment plan.

The following are evidence-based assessment tools for youth with obsessive-compulsive disorder:

## **Broad Structured Diagnostic Interviews:**

- National Institute for Mental Health (NIMH) Diagnostic Interview Schedule for Children-IV (DISC-IV; NIMH, 1997)
- Schedule of Affective Disorders and Schizophrenia for School Aged Children, Present and Lifetime Version (K-SADS-PL; Kaufman et al., 1996)

# Anxiety-specific Structured Diagnostic Interviews:

- Anxiety Disorders Interview Schedule for *DSM-IV*: Parent and Child Versions (ADIS-IV:C/P; Silverman & Albano, 1996)
- Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS; Scahill, Riddle, & King, 1997)
- Children's Version of the Leyton Obsessional Inventory (Berg et al., 1988)

# **Body Dysmorphic Disorder**

Obsessive thoughts about perceived physical flaws and compulsive behaviors and avoidances related to how youths perceive their appearance can signal the presence of body dysmorphic disorder in youth. Developmental changes in the adolescent brain may contribute to the onset of body dysmorphic disorder (Phillips & Rogers, as cited by Smith, 2011). These changes increase adolescents' self-consciousness and awareness of social status. Therefore, body dysmorphic disorder may be a disordered response to the psychological, social, and physical changes of adolescence itself. It is important that the clinician distinguishes normal adolescent concerns from body dysmorphic disorder concerns.

The following are commonly utilized assessment tools for body dysmorphic disorder (Smith, 2011; Phillips, et al., 2013):

- Body Dysmorphic Disorder Questionnaire; (BDDQ)
- Body Dysmorphic Disorder Examination (BDDE)
- Yale-Brown Obsessive-Compulsive Scale modified for Body Dysmorphic Disorder (BDD-YBOCS)
- Body Dysmorphic Disorder Diagnostic Module for Adolescents
- Brown Assessment of Beliefs Scale (BABS)

The BDD-YBOCS is a semi-structured interview allowing for further probing and discussion by the clinician. Because the BDD-YBOCS measures severity rather than strictly being a differential diagnostic tool, instructions indicate that clinicians must first be fairly certain that the person has body dysmorphic disorder. However, the BDD-YBOCS can yield valuable information about obsessions, compulsions, insight, avoidance, and severity (Smith, 2011). Special care must also be taken when individuals with body dysmorphic disorder seek cosmetic surgery or enhancement. Only the Body Dysmorphic Disorder Questionnaire-Dermatology Version (BDDQ-DV) and the Dysmorphic Concern Questionnaire (DCQ) have been validated for those individuals seeking cosmetic surgery or enhancement, but they have not been specifically tested in youth (Picavet, Gabriëls, Jorissen & Hellings, 2011).

# **Hoarding Disorder**

Hoarding disorder was previously considered one of many symptoms of OCRD. As a separate disorder, independent evaluation and assessment is in its scientific infancy and will need to be further developed and studied for efficacy. A number of tests have been developed to determine the presence of hoarding disorder, although none meets the strict standards of evidence-based assessment tools at this point.

The following are the rating systems used to assess hoarding disorder (Kennedy & O'Neill, 2012; Nordsletten et al., 2013):

- Activities of Daily Living in Hoarding scale (ADL-H)
- HOMES Multi-disciplinary Hoarding Risk Assessment
- Clutter-Hoarding Scale
- Clutter Image Rating (CIR)
- Saving Inventory-Revised (SIR)
- Structured Interview for Hoarding Disorder (SIHD)
- Hoarding Rating Scale Interview (HRS-I)
- Hoarding Rating Scale Self Report (HRS-SR)
- Saving Inventory Revised (SI-R)

The Activities of Daily Living-Hoarding (ADL-H) assesses how difficult the individual finds completing activities of daily living. The difficulties are based upon clutter or hoarding, living conditions, and safety considerations (Kennedy & O'Neill, 2012). The Clutter Hoarding Scale looks at five levels of organization within the home, and it is designed for use by professional

organizers or clinicians (Institute for Challenging Disorganization [ICD], 2011). The five areas studied by the Clutter Hoarding Scale are structure and zoning, including ingress and egress and heating and electrical; animals and pests, including pets and infestations of rodents or insects; household functions, including safety, functionality and accessibility of rooms; health and safety including sanitation and medication management; and personal protective equipment, which recommends gloves, masks and respirators where appropriate (ICD). The Clutter Image Rating (CIR) cycles through pictures of a room at varying levels of clutter. This scale is used to help people self-evaluate the severity of the problem (International Obsessive-Compulsive Disorder Foundation [IOCDF], 2013) and helps clinicians directly observe the severity of clutter (Tolin, Frost & Steketee, 2010). The Saving Inventory-Revised (SIR) is considered, along with the CIR, to demonstrate good psychometric properties, and both seem useful in clinical and research settings (Tolin, Frost, & Steketee). The Structured Interview for Hoarding Disorder (SIHD) assesses the individual's home room by room and does an in-depth evaluation of its clutter (Kennedy & O'Neill). The interview assesses the comfort level of the individual with his or her hoarding and determines its impact on the lifestyle of the hoarder (Pertusa, Frost, & Mataix-Cols, 2010).

Historically, the Yale-Brown Obsessive-Compulsive Scale (Y-BOCS) has assessed hoarding severity; however, it only includes two questions with yes or no answers to assess hoarding (Tolin, Frost & Steketee, 2010). One rating scale that has gained scientific recognition for evaluating adults is the Hoarding Rating Scale Interview (HRS-I). It consists of five initial questions, with probing follow-up questions as needed at the clinician's discretion. The questions gauge how clutter impacts the use of a living space, the difficulty of discarding possessions, excessive acquisition, emotional distress from the behaviors, and functional impairment (Tolin, Frost, & Steketee). The HRS-I is especially beneficial in that the clinician can determine both whether the individual meets the standards for hoarding and the severity of the hoarding (Tolin, Frost & Steketee). As mentioned above, these tools may gain additional support as they are further studied.

# Trichotillomania (Hair-Pulling Disorder)

Assessment of trichotillomania should measure severity, subtypes, level of impairment, and possible comorbid diagnoses (Woods et al., 2006). Assessing trichotillomania may require multiple methods of gathering information, including interviews with youth and a parent. Unfortunately, although some scales do exist, there has been relatively little research on measures of child trichotillomania. The National Institute of Mental Health (NIMH) Trichotillomania Impairment Scale (NIMH-TIS) is a clinician-rated scale that has demonstrated adequate psychometric profiles (Woods et al.). Also, the Trichotillomania Scale for Children, the Child Report (TSC-C) and Parent Report (TSC-P) and Milwaukee Inventory for Styles of Trichotillomania (MIST-C) show promise as a parental tool and self-report measure (McGuire et al., 2012). The former measures the severity of the pulling along with distress and/or impairment, while the latter assesses whether the pulling is focused or automatic (McGuire et al.).

Table 2 outlines evidence-based assessment tools for youth with trichotillomania.

Table 2
Evidence-based Assessment Tools for Youth with Trichotillomania

Name of Measure	Measure Type	Who Completes	Data Generated
Psychiatric Institute Trichotillomania Scale (PITS)	Clinician rating scale	Clinician	Symptom rating
National Institutes of Mental Health Trichotillomania Impairment Scale (NIMH-TIS)	Clinician rating scale	Clinician	Symptom impairment
Trichotillomania Scale for Children (TSC-C)	Self-report rating scale	Youth	Symptom rating
Trichotillomania Scale for Children (TSC-P)	Parent-report rating scale	Parent	Symptom rating
Milwaukee Inventory for Styles of Trichotillomania (MIST-C)	Self-report rating scale	Youth	Symptom specifier

Sources: Chorpita & Southam-Gerow, 2006; Woods et al., 2006; McGuire et al., 2012.

# **Excoriation (Skin-Picking Disorder)**

Unfortunately, there are no psychometric evaluations of any assessment tools for youth with excoriation. In adults, the Skin Picking Scale (SPS) tests the frequency and severity of symptoms. The Skin Picking Impact Scale (SPIS) tests the impact of picking, rather than its severity. The Milwaukee Inventory for Dimensions of Adult Skin Picking (MIDAS) is a self-report, and it assesses both automatic and focused skin picking. Each of the preceding tests shows some consistency in adults, but none have been evaluated for test-retest reliability (McGuire et al., 2012).

# Comorbidity

While obsessive-compulsive disorder, hoarding disorder, body dysmorphic disorder, trichotillomania, and excoriation are classified together as OCRD, comorbid disorders may vary among each subtype. The disorders that commonly co-occur with these subtypes will be outlined in the following paragraphs. Additional information about the comorbid disorders discussed in this section can be found in the corresponding sections of the *Collection*.

# **Obsessive-Compulsive Disorder**

Comorbid conditions that often occur in youth with obsessive-compulsive disorder include other anxiety disorders, depression, learning disorders, attention deficit hyperactivity disorder (ADHD), and tic disorders. It is estimated that 20 to 70 percent of youth with obsessive-

compulsive disorder meet the criteria for mood disorders, potentially due to the impairment and isolation associated with the disorder (AACAP, 1998; March & Mulle, 1998). As many as 33 to 50 percent of youth with obsessive-compulsive disorder meet diagnostic criteria for ADHD or oppositional defiant disorder (ODD). However, clinicians must determine whether oppositional behaviors are a function of ODD or of the rigid compulsions associated with obsessive-compulsive disorder (AACAP, 1998). Up to 30 percent of children with OCRD report a lifetime history of tic disorder (APA, 2013a). The *DSM-5* points out that this comorbidity is most common for males with obsessive-compulsive disorder in childhood.

Obsessive-compulsive disorder is also more prevalent in individuals who also have certain mental health disorders. Obsessive-compulsive disorder prevalence is 12 percent in those with schizophrenia or schizoaffective disorder, and significant in those with bipolar disorder, eating disorders like anorexia nervosa and bulimia nervosa, and Tourette disorder (APA, 2013b). Some researchers believe that obsessive-compulsive disorder and tic disorders like Tourette's disorder may be alternative expressions of the same gene (AACAP, 1998). Children with pre-pubertal onset of obsessive-compulsive disorder are more likely to have a comorbid diagnosis of tic disorder.

Obsessive-compulsive symptoms are also common features of autism spectrum disorder (ASD). Because rigidity and repetitive behaviors are central features of ASD, it can be difficult to determine whether comorbid obsessive-compulsive disorder is present. However, research suggests that obsessive-compulsive symptoms are frequently present in first degree relatives of youth with an ASD diagnosis (AACAP, 1998).

# **Body Dysmorphic Disorder**

Several disorders are often comorbid with body dysmorphic disorder. These also include the most commonly comorbid disorders: major depression, social phobia, and substance use disorders (Feusner, Winograd, & Saxena, 2005; APA, 2013a). It is also frequently comorbid with obsessive-compulsive disorder. Major depressive disorder often presents after body dysmorphic disorder onset (APA).

# Hoarding Disorder

Hoarding disorder is often comorbid with several different disorders, and like body dysmorphic disorder, it is frequently comorbid with obsessive-compulsive disorder with almost 20 percent comorbidity (APA, 2013a). Individuals with hoarding disorder may also present with schizophrenia, dementia, eating disorders, autism, and intellectual disability (Saxena, 2007). It may also present with non-clinical levels of symptoms for some or all of these disorders (Saxena). The *DSM-5* notes that as many as 75 percent of individuals with hoarding disorder also have a mood or anxiety disorder.

## Trichotillomania and Excoriation

Youth with trichotillomania and excoriation often experience other psychological problems (Woods et al., 2006). Research suggests that 60 to 70 percent of youth with trichotillomania meet the criteria for at least one additional psychiatric disorder, with anxiety and affective disorders being the most frequently diagnosed (Tolin et al., 2007). Trichotillomania and excoriation are

more common in individuals with first degree relatives diagnosed with obsessive-compulsive disorder (APA, 2013a). Excoriation often accompanies trichotillomania or obsessive-compulsive disorder and it may accompany major depressive disorder (APA).

## **Treatments**

An overview of treatments for the *DSM-5* categories of OCRD will be highlighted in the following section. Behavioral and pharmacological treatments have demonstrated efficacy in the treatment of OCRD in youth, though behavioral approaches appear to be the most effective in the few studies comparing treatments (AACAP, 1998; Barrett et al., 2008).

# **Obsessive-Compulsive Disorder**

Individual features of obsessive-compulsive disorder may have important implications for treatment planning in terms of compliance, response to treatment, and factors that exacerbate or lessen symptoms (AACAP, 1998). Mild obsessions or compulsions that are not the source of substantial distress or impairment may warrant monitoring over time without the initiation of specific treatment (AACAP, 1998). If such obsessions or compulsions are related to external or developmental stressors, psychotherapy or other psychosocial interventions targeted to these stressors may be useful. Treatments for obsessive-compulsive disorder are discussed are outlined in Table 3.

# **Psychosocial Treatments**

Effectively treating obsessive-compulsive disorder in youth is crucial to aiding in their lifelong functioning. The process of assessment and treatment planning can also be beneficial. The opportunity to review the child's difficulties and to distinguish the obsessive-compulsive disorder symptoms as a disorder, rather than as a behavior issue, can be very helpful to both the child and family (AACAP, 1998).

Cognitive Behavioral Training (CBT) is the clinical standard first treatment path for obsessive-compulsive disorder in youth (AACAP, 2012). Clinicians should treat mild to moderate cases of obsessive-compulsive disorder youth with CBT, and for moderate to severe cases, CBT should accompany pharmacotherapy (AACAP, 2012). Both individual and individual family-based CBT treatments have been shown to be effective.

The CBT protocol used in the National Institute of Mental Health Pediatric Obsessive-Compulsive Disorder Treatment Study (POTS) requires 14 visits in 12 weeks. The visits are broken into the following five phases:

- 1. Psychoeducation
- 2. Cognitive training
- 3. Mapping obsessive-compulsive disorder
- 4. Exposure and response prevention (ERP)
- 5. Relapse prevention and generalization training (AACAP, 2012; March et al., 2004)

During each session, the clinician and youth state the goals for the session, review the preceding week, practice skills, prepare homework and devise monitoring procedures to prevent obsessive-

compulsive disorder symptoms (AACAP, 2012; March et al., 2004). The affected youth visits the clinician twice in the first two weeks, and then once weekly, with a telephone call visit between in person visits.

Table 3
Summary of Treatments for Obsessive-Compulsive Disorder

What Works	
Cognitive behavioral therapy (CBT) with exposure and response prevention (ERP)	Treatment path with a consistent and compelling relationship between the disorder, the treatment, and the specified outcome. Combines training with exposure and preventing the accompanying response.
Family-focused individual CBT	Individual CBT that includes a focus on family involvement. It should be noted that the distinction of family focused here is meant to imply a format for treatment delivery.
SRIs	Clomipramine: Approved for children aged ten and older. Recommend periodic electrocardiographic (ECG) monitoring.
SSRIs	Fluoxetine (Prozac): Approved for children aged eight and older Sertraline (Zoloft): Approved for children aged six and older Fluvoxamine (Luvox): Approved for children aged eight and older
What Seems to Work	
Family focused group CBT	Studies show promising results but there have only been a small number of studies. However, each study addresses complex comorbidity and issues impacting community-based clinic treatment.
Not Adequately Tested	
CBT without ERP Psychodynamic therapy Client-centered therapy	Systematic controlled studies have not been conducted using these approaches.
Technology-based CBT	Results show preliminary support for telephone CBT and web-camera CBT. Although these results are encouraging, caution must be taken due to the small sample sizes and lack of active control groups.
What Does Not Work	
Antibiotic treatments	Antibiotic treatments are only indicated when the presence of an autoimmune or strep-infection has been confirmed and coincided with onset or increased severity of obsessive-compulsive disorder symptoms.
Herbal therapies	Herbs, such as St. John's Wort, have not been rigorously tested and are not FDA approved. In some instances, herbal remedies may make symptoms worse or interfere with pharmacological treatment.

Sources: AACAP, 1998; Barrett et al., 2008; March & Mulle, 1998; AACAP, 2012; EffectiveChildTherapy.com, 2014; Society of Clinical Child & Adolescent Psychology (SCCAP), 2014.

The ERP phase of CBT treatment was developed as a bi-modal treatment that addresses both the obsessive and compulsive features of obsessive-compulsive disorder. AACAP has noted that ERP is now an integral component of CBT. Accordingly, ERP-based CBT is a standard clinical

treatment for pediatric obsessive-compulsive disorder (AACAP, 2012). Most studies evaluated the effectiveness of ERP-based CBT techniques (e.g., relaxation training, cognitive restructuring). When the ERP exposures were present in treatment, they were the main treatment variables, but the other components of CBT were also necessary for the effectiveness of the treatment (March, Mulle & Herbel, 1994). The overall results of these studies suggest that ERP-based CBT is effective in significantly reducing symptoms in children and adolescents. In fact, research suggests that ERP-based CBT may be more effective than pharmacological treatments (Barrett et al., 2008). All studies found statistically and/or clinically significant reductions in symptoms using ERP-based CBT. Most studies directly used or modified the manual by March and Mulle (1998) (Benazon, Ager, & Rosenberg, 2002; DeHaan et al., 1998; March, Mulle, & Herbel, 1994; Pediatric OCD Treatment Study [POTS], 2004; Simons, Schneider, & Herpertz-Dahlmann, 2006; Thienemann et al., 2001; Valderhaung et al., 2007).

## Pharmacological Treatment

Although traditionally used to treat depression, serotonin reuptake inhibitors (SRIs), including selective serotonin reuptake inhibitors (SSRIs), are approved by the FDA for treatment of pediatric obsessive-compulsive disorder (AACAP, 1998). There are currently four medications approved by the FDA for treatment of pediatric obsessive-compulsive disorder: the SSRIs fluoxetine, sertraline, and fluvoxamine, and the SRI clomipramine, a tricyclic antidepressant. However, no studies have compared the efficacy of the four drugs (AACAP, 1998; AACAP, 2012). AACAP recommends concurrent pharmacological treatment and CBT for children with severe symptoms, for children too ill to participate in CBT, or for those who do not respond favorably to CBT alone (2012). These medications have been shown to be significantly more effective compared to placebo treatments. Although all of these treatments act on availability of serotonin in the brain, evidence suggests that children may respond differently to different medications (AACAP, 1998). Therefore, youth who do not respond to one SSRI may respond differently to another.

While these medications may be helpful, they are not without risks and side-effects. In high doses (5mg/kg per day or 250mg/day), clomipramine has been associated with seizures and electrocardiographic (ECG) changes. Youth taking clomipramine should receive periodic ECG monitoring. Other side effects of clomipramine include dry mouth, constipation, dizziness, postural hypotension, sweating, and sedation (AACAP, 2012). There has also been greater awareness of an increased risk of suicidal ideation in youth taking antidepressants, including SSRIs. These risks must be weighed against the potential benefit from the medication when making treatment decisions. Youth taking these medications should be monitored for potential medical or psychological side-effects throughout treatment, particularly if other medications are also prescribed. The interaction of medications is poorly researched, particularly in children and adolescents; therefore, combinations of medications should be carefully considered (AACAP, 1998). For additional information on this topic, please refer to the *Collection's* section "Antidepressants and the Risk of Suicidal Behavior."

# **Unproven Treatments**

Several treatments are classified as unproven, based on either the absence of conclusive research or research suggesting that there is no benefit. Cognitive therapy, in the absence of ERP, has not

demonstrated significant benefits for youth with obsessive-compulsive disorder. The addition of cognitive therapeutic techniques to ERP treatment has suggested that these techniques may increase treatment participation in ERP, but perform no specific action on reducing symptoms (Barrett et al., 2008). Likewise, insight-oriented therapies have not been shown to be effective in treating youth with obsessive-compulsive disorder.

As discussed in the Causes and Risk Factors section of this review, there is a subset of children who develop obsessive-compulsive disorder following a strep-infection (e.g., PANDAS). For these children, treatments with antibiotics reduce symptoms. However, antibiotic treatment does not prevent obsessive-compulsive disorder without a strep infection being present (Gilbert, 2008). Therefore, antibiotic treatment should only be prescribed for children with a confirmed medical diagnosis that leads to the sudden onset or increase of obsessive-compulsive disorder symptoms (AACAP, 1998). Herbal remedies have not been sufficiently tested as a treatment for obsessive-compulsive disorder. St. John's Wort, frequently used by some to treat mild depression, is a popular alternative treatment for anxiety, including obsessive-compulsive disorder. However, a blind placebo-controlled study found no difference between St. John's Wort and the placebo (Kobak et al., 2005).

One treatment gaining attention for obsessive-compulsive disorder is Deep Brain Stimulation (DBS). DBS is also being tested for use in depression and anorexia, and is showing success in very small scientific studies (Stetka & Correll, 2013). In addition, a small study of adults with obsessive-compulsive disorder showed a positive response to intravenous ketamine infusion (Stetka & Correll; Rodriguez et al., 2013). These treatments are in their infancy, but may gain strength in the future.

# Trichotillomania (Hair-Pulling Disorder) and Excoriation (Skin-Picking Disorder)

Research exploring treatments for childhood trichotillomania and excoriation is promising, but the treatments have not been researched sufficiently enough to warrant the designation of evidence-based treatment. These and other treatments are summarized in Table 4 and discussed more fully in the paragraphs that follow.

CBT is emerging as a promising treatment for trichotillomania. CBT for trichotillomania involves many components common to habit reversal therapy (HRT) such as awareness training and developing a competing response. However, CBT treatments also incorporate several additional elements like psychoeducation and cognitive skills that are thought to provide additional benefits. Psychoeducation entails teaching youth and parents about hair pulling and how to monitor behavior. Cognitive restructuring helps youth identify and change maladaptive beliefs associated with stressful situations and to distinguish between minor setbacks and full-blown relapses. CBT for trichotillomania also includes a relapse prevention component that encourages the maintenance of learned behaviors after the end of the active treatment phase (Tolin, Franklin, Diefenbach, Anderson & Mercer, 2007).

Components have also been added to HRT to target additional problems. In the treatment of trichotillomania and excoriation, therapists may employ either emotion-regulation techniques, which help youth learn more adaptive ways of coping with emotion, or cognitive restructuring,

which helps youth recognize and change the thoughts or emotions that occur before or after pulling or picking (Woods, Flessner, & Conelea, 2008).

CBT may be superior to pharmacotherapy, pill placebo, wait-list, and supportive therapy in treating trichotillomania according to recent adult studies (Flessner, 2011). At the core of CBT is HRT, the three main components of which are:

- 1. Awareness training;
- 2. Competing response training; and
- 3. Social support (Flessner; Woods, Flessner & Conelea, 2008).

There are still no clear evidence-based pharmacological interventions to treat trichotillomania in children (Flessner, 2011).

 ${\it Table \ 4}$  Summary of Treatments for Trichotillomania and Excoriation by Level of Support

What Works		
There are no evidence-based practices at this time.		
What Seems to Work		
Habit reversal therapy (HRT)	Treatment increases awareness to the feelings and context associated with the urges and implements a competing and inconspicuous habit in place of the hair pulling and skin picking.	
Cognitive behavioral therapy (CBT) for trichotillomania	Treatment involves exposing children to the stimuli associated with the urge, while challenging thoughts associated with high-risk situations.	
Not Adequately Tested		
SSRIs N-acetylcysteine Naltrexone	Some demonstrated improvement on certain measures of picking behavior has been demonstrated in some pharmacological studies.	

Sources: Tolin et al., 2007; Grant et al., 2012.

# **Body Dysmorphic Disorder**

Unfortunately, there are no evidence-based treatments yet available for youth with body dysmorphic disorder. CBT has not been investigated on a large enough scale to provide results with great external validity, but shows promise because of its effectiveness with similar disorders (Phillips & Rogers, 2011).

Evidence suggests obsessive-compulsive disorder, major depressive disorder and social phobia are effectively treated with pharmacotherapy. Therefore, because of body dysmorphic disorder's similarities to the aforementioned disorders, scientists posit that pharmacotherapy may be appropriate to treat body dysmorphic disorder (Phillips & Hollander, 2008). However, there are currently no studies that meet evidence-based standards to support this idea (Phillips &

Hollander). SSRIs are possibly efficacious treatments for body dysmorphic disorder, and fluoxetine has shown some efficacy (Bjornsson, Didie & Phillips, 2010).

# Hoarding Disorder

Unfortunately, no treatments that meet the level of evidence-based standards are available for youth with hoarding disorder. Historically, hoarding as a symptom of OCRD did not react well to medication or CBT (Saxena & Maidment, 2007). Although no treatment path has yet been developed, a combination of (1) discarding excess possessions; (2) organizing remaining possessions; (3) planning to prevent new acquisitions; and (4) introducing alternative behaviors have shown some success (Saxena & Maidment). Treatment may include education about hoarding, setting goals, enhancing motivation, training decision making skills, and practice sorting and organizing. This can be coupled with discarding old possessions and preventing acquisition of new possessions (Steketee, 2014).

#### **Cultural Considerations**

This portion of the *Collection* explores the effect, if any, of culture on the symptoms, presentation, and treatment of OCRD.

# **Obsessive-Compulsive Disorder**

Research is extremely limited on the role of culture and ethnicity in obsessive-compulsive disorder. Although the physiological symptoms are universal, the way in which the experience is interpreted and expressed varies as a function of culture (Washington, Norton, & Temple, 2008). Culture also influences help-seeking behaviors and treatment preferences (Sue, Zane, & Young, 1994). Clinicians should consider, but not assume, cultural influences to ensure proper identification and treatment.

Clinicians should be familiar with the ways in which youth and families conceptualize symptoms. Cultural practices and norms shape the way in which emotions are understood and expressed. This can lead to differences in attributions of emotions and behaviors, expressions of symptoms, and the language used to describe the symptoms. Clinicians and researchers who are unaware of culture-specific idioms of distress may fail to notice important symptoms, dismiss symptoms as irrelevant, or misattribute the symptoms to a different diagnosis. Normative cultural practices should also be considered to avoid characterizing certain behaviors as psychologically abnormal (March & Mulle, 1998). For example, research on standardized measures has demonstrated that African American individuals report higher levels of cleaning and checking symptoms, but do not report anxiety and/or impairment surrounding these symptoms. Thus, they do not always meet diagnostic criteria for obsessive-compulsive disorder during structured interviews (Thomas, Turkheimer, & Oltmanns, 2000; Williams et al., 2005). Similarly, South Asian/East Indian and Southeast Asian individuals are more likely to report obsessivecompulsive symptoms compared to Caucasian, African American, and Latino individuals (Washington, Norton, & Temple, 2008). However, these elevated reports of obsessivecompulsive symptoms were only associated with obsessive-compulsive disorder distress and impairment in South Asian/East Indian individuals. Elevated reports of obsessive-compulsive

symptoms in Southeast Asian individuals were not associated with increased incidence of obsessive-compulsive disorder (Washington, Norton, & Temple).

Ethnicity may also play a role in attribution biases of African American youths' behaviors. Lau and colleagues (2004) found that, while African American youth reported slightly higher levels of their own internalizing symptoms compared to Caucasian youth, teachers rated Caucasian students as having higher anxiety and African American students with higher externalizing symptoms. Some children with OCRD may refuse to approach feared situations or have tantrums when compulsions are interrupted or prevented, which may lead observers to interpret this behavior as oppositional behavior (Klein, 2009). Teachers may interpret anxious refusal as oppositional-defiance based on racial stereotypes (Lau et al.).

Literature on pediatric ERP-based CBT treatment is limited because of the exclusion of racial/ethnic minorities and/or participants of various socioeconomic statuses. Only seven studies reported racial/ethnic demographics; four of these were entirely Caucasian, while the others still underrepresented minorities. No studies reported socioeconomic status of the participants. While OCRD prevalence is approximately equal across ethnicities, the representation in randomized clinical trials is heavily weighted to Caucasians (Williams, Powers, Yun & Foe, 2010). Some researchers posit that, along with institutional mistrust, ethnic minorities may not participate in randomized clinical trials because of financial barriers, language barriers, proximity to specialty clinics, and cultural beliefs about the best approaches to mental illness.

Factors such as cultural or social stigma and availability of social and economic resources may impact a family's ability to access treatment and/or conduct CBT with ERP at home. This limits the ability to generalize results of these studies for use in community-based clinics that serve minority and economically disadvantaged patients. General recommendations for adapting treatments to be culturally sensitive apply to the treatment of OCRD in the absence of specific research on treatment for OCRD and individual racial/ethnic/cultural groups. In a recent review of evidence-based treatments and modifications for ethnic minority youth, treatments discussed were the selective use of culturally responsive adaptations based on actual client need and avoidance of overgeneralizations based on race/ethnicity/culture (Huey & Polo, 2008).

## **Body Dysmorphic Disorder**

Body dysmorphic disorder appears across cultures (APA, 2013a). Symptoms may present differently, as Caucasians may be more concerned with body issues where Asian Americans may be more concerned with hair and skin (Marques et al., 2011). Additionally, cultural values may affect the concerns of individuals with body dysmorphic disorder (APA).

## Hoarding Disorder

Most research on hoarding disorder has been done in western industrialized countries, specifically in urban areas, but data available from non-western industrialized countries suggest that hoarding disorder is universal and presents consistently across cultures (APA, 2013b; Samuels et al., 2008).

#### Trichotillomania and Excoriation Disorder

Research suggests rates of trichotillomania are similar between Caucasians and African Americans, and German and American samples demonstrate equivalent rates of excoriation (Woods, Flessner & Conelea, 2008). There is little research on cultural differences affecting trichotillomania. However, one study of trichotillomania in African American women showed that trichotillomania rates positively correlated with anxiety levels in college students in the sample (Neal-Barnett, Statom, & Stadulis, 2011).

Some research suggests that excoriation most frequently occurs in females from teens to late 30s (APA, 2013a). While excoriation is significantly more frequent in females than males, it appears to be consistent across cultures. More research must be done to confirm this finding.

#### **Overview for Families**

Children or adolescents with OCRD will often do certain actions or behaviors to ease anxiety caused by obsessive thoughts. Often, the obsessive thoughts (also called obsessions) are irrational and/or unrealistic. The actions or behaviors (called compulsions) are a temporary escape from stress and anxiety. Compulsions can include the following:

- Constant hand washing
- Hoarding
- Repeated ordering of items
- Checking things repeatedly
- Counting or repeating actions a certain number of times or until it "feels right"

Families who suspect a youth may have OCRD should look out for the following:

- Repetitive and obsessive thoughts that persist;
- Urges that result in repetitive behaviors; and
- The youth being driven to perform these behaviors as a result of the obsessive thoughts.

OCRD tends to run in families, but it may develop even without any previous family history. As many as 40 percent of youth with childhood or adolescent-onset OCRD may have remission in adulthood.

Disorders included in the OCRD category include:

- Obsessive-compulsive disorder
- Body dysmorphic disorder
- Trichotillomania (hair-pulling disorder)
- Excoriation (skin-picking disorder)
- Hoarding disorder

Obsessive-compulsive and related disorder due to another medical condition and obsessive-compulsive and related disorder that is substance/medication-induced are also included in this category. Data on these subtypes is limited.

Signs of OCRD include obsessively seeking out things that are "just right." This could be physical ("just right" clothing or body positioning) or based on perception (things feeling "just right"). A youth with OCRD may also seek completeness or accuracy. However, it is important to note that many behaviors similar to those seen in OCRD are a normal part of child development. Therefore, proper assessment by a licensed clinician is imperative to make an accurate diagnosis.

Most children with OCRD can be treated effectively with a combination of psychotherapy (especially cognitive and behavioral techniques) and certain medications (such as selective serotonin reuptake inhibitors (SSRI's)). Family support and education are also central to the success of treatment. Antibiotic therapy may be useful in cases where OCRD is linked to streptococcal infection. Seeking help from a child psychiatrist/psychologist and/or adolescent psychiatrist/psychologist is important both to better understand the complex issues created by OCRD as well as to get help.

As many as an estimated 10 percent of patients with OCRD attempt suicide in adolescent and adult years. While this risk does not solely affect children and adolescents, families should be aware of this risk and monitor their children for signs of suicidal ideation (thinking about suicide). For additional information on this topic, families should consult the "Youth Suicide" section of this *Collection*.

# **Resources and Organizations**

American Academy of Child & Adolescent Psychiatry (AACAP)

https://www.aacap.org/

**Anxiety Disorders Association of America (ADAA)** 

https://adaa.org

#### **International OCD Foundation**

https://iocdf.org

## **Mayo Clinic**

Obsessive Compulsive Disorder

https://www.mayoclinic.org/diseases-conditions/obsessive-compulsive-disorder/symptoms-causes/syc-20354432

#### **Mental Health America (MHA)**

Obsessive-Compulsive Disorder

http://www.mentalhealthamerica.net/conditions/ocd

Tricholtillomania

http://www.mentalhealthamerica.net/conditions/trichotillomania-hair-pulling

## **National Alliance on Mental Illness (NAMI)**

https://www.nami.org/

## **National Anxiety Foundation**

Obsessive Compulsive Disorder

http://www.nationalanxietyfoundation.org/ocd.html

#### **National Institute of Mental Health (NIMH)**

Obsessive Compulsive Disorder

https://www.nimh.nih.gov/health/topics/obsessive-compulsive-disorder-ocd/index.shtml https://www.nimh.nih.gov/health/publications/obsessive-compulsive-disorder-when-unwanted-thoughts-take-over/index.shtml

#### **National Mental Health Information Center**

https://www.mentalhealth.gov/

#### **Obsessive-Compulsive Disorder in Children and Adolescents**

https://www.aacap.org/AACAP/Families\_and\_Youth/Facts\_for\_Families/FFF-Guide/Obsessive-Compulsive-Disorder-In-Children-And-Adolescents-060.aspx

#### **Obsessive-Compulsive Foundation**

https://iocdf.org/

## Parent Support Groups for Children with OCD

http://www.childrensdisabilities.info/OCD/groups-OCD-child.htm

## **TLC Foundation for Body-Focused Repetitive Behaviors**

http://www.bfrb.org/index.php

#### U.S. Department of Health and Human Services

Substance Abuse and Mental Health Services Administration (SAMHSA)

http://www.samhsa.gov/

## Virginia Resources and Organizations

## National Alliance on Mental Health (NAMI) Virginia

https://namivirginia.org/

## Virginia Commonwealth University (VCU) Medical Center

Virginia Treatment Center for Children

https://www.chrichmond.org/Services/Mental-and-Behavioral-Health.htm?vtcc=true

## Virginia Department of Behavioral Health and Developmental Services (DBHDS)

http://www.dbhds.virginia.gov/

## **Virginia Polytechnic Institute and State University (VA Tech)**

Psychological Services Center

http://www.psyc.vt.edu/outreach/psc

Child Study Center

https://www.psyc.vt.edu/labs/csc

## University of Virginia Health System

https://neurosciences.uvahealth.com/services/psychiatry/mental-health-conditions/anxiety-disorders

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# RAUMA- AND STRESSOR-RELATED DISORDERS

Introduction

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#### Introduction

Overview for Families

Trauma is a lasting adverse effect on an individual caused by an event that involves threat or danger. Events are not traumatic simply because they involve violence; instead, an individual's perception of threat or danger is what can cause trauma (Berliner, 2013). According to the *DSM*-5, trauma can result when an individual directly experiences an adverse event, witnesses that event, or learns about it from others.

Exposure to trauma is very common. Each year, approximately 60 percent of children experience at least one trauma, with about 22 percent of these youth experiencing four or more different types of traumas (Finkelhor, as cited by Berliner, 2013). Because a significant number of youth experience some type of traumatic incident during childhood, it is critical to identify definitions of, risk factors for, and outcomes from exposure to trauma (Copeland, Keeler, Angold, & Costello, 2007).

Early researchers noted that exposure to trauma may lead to feelings of anxiety, helplessness, dissociation (detachment of the mind from emotion), and behaviors, including hypervigilance (watchfulness or awareness of one's surroundings over and above what is normal), efforts to avoid re-experiencing the traumatic event, and even self-inflicted injury (Yates, 2004; Thomas, 2003). While these symptoms may be consequences of trauma, they do not always occur following trauma. Additionally, risk factors can moderate the influence of trauma as well as the development of psychopathology.

Trauma- and stressor-related disorders are those disorders precipitated by events or circumstances that overwhelm the child or adolescent and that often threaten or cause serious injury, neglect, or death (American Psychiatric Association [APA], 2015). This section will discuss trauma- and stressor-related disorders and focus on the assessment and treatment of these disorders

#### **Definitional Considerations**

Beginning in the 1970s, psychologists began to examine the experiences of individuals who have experienced traumatic events, with research focusing on both soldiers returning from war and rape victims (Copeland, Keeler, Angold, & Costello, 2007). This work has contributed greatly to the understanding of psychopathology (van der Kolk et al, 2005). However, early research was limited in that it focused almost exclusively on individuals in the military who experienced traumatic events outside of their home community and ignored the experiences of traumatic events in everyday life, including their effects upon children (Karam & Ghosn, 2003). Additionally, early definitions of trauma emphasized the individual directly experiencing the violent act, such as military personnel in war or rape victims (Copeland, Keeler, Angold, & Costello) and discounted the distress experienced by those who did not directly experience the trauma, such as a family member witnessing domestic violence (Evans, Davies, & DiLillo, 2008). The definition of trauma was subsequently broadened due to the recognition that indirect experiences can be traumatic, youth also experience trauma, and youth respond to trauma differently than adults (Carrion, Weems, Ray, & Reiss, 2002).

## Recent Changes from the DSM-IV to the DSM-5

In 2013, the American Psychiatric Association released the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*). The *DSM-5* reorganized trauma- and stressor-related disorders into a new category. Changes were made to differentiate these disorders from anxiety disorders as well as restructure and modify various factors and symptoms (Jones & Cureton, 2014). Posttraumatic stress disorder (PTSD) and acute stress disorder (ASD) were formerly categorized as anxiety disorders but are now included as trauma- and stressor-related disorders. This category reconceptualizes various diagnoses as stress-response syndromes in reaction to specific triggering events (Kurtz, 2013). The diagnoses now included in the trauma- and stressor-related disorder category are:

- PTSD:
- ASD;
- Adjustment disorder;
- Reactive attachment disorder (RAD) (diagnosed only in children);
- Disinhibited social engagement disorder (DSED) (diagnosed only in children);
- Other specified trauma- and stressor-related disorder; and
- Unspecified trauma- and stressor-related disorder.

The most significant changes in the *DSM-5* were to the PTSD and ASD criteria, including the removal of the *DSM-IV* requirement of feelings of "fear, helplessness, or horror" in reaction to the traumatic event (APA, 2013; APA, 2000). Changes relative to just PTSD include the inclusion of two new variations (Preschool subtype and Dissociative subtype) and the addition of

new symptom clusters. Additional changes included in the *DSM-5* will be discussed in the paragraphs that follow.

The *DSM-5* is a manual for assessment and diagnosis of mental health disorders and does not include information for treatment of any disorder. In the future, more evidence supporting treatments of disorders with *DSM-5* classifications will be available as clinical studies utilizing *DSM-5* criteria are completed. As a result, this *Collection* will reference studies that utilize *DSM-IV* diagnostic criteria to explain symptoms and treatments.

#### **Prevalence**

It has been difficult to come to a consensus on the prevalence of trauma among children. Evans, Davie, and DiLillo (2008) estimate that each year 4.8 million acts of violence are committed against women and 2.9 million acts of violence are committed against men. Not only do these experiences have a profound effect on these individuals, they may also affect others, including children exposed to this violence. It is estimated that each year 17.8 million children are exposed to domestic violence, either as witnesses or as targets (Evans, Davies, & DiLillo). Moreover, retrospective data suggests that 20 to 40 percent of adults witnessed domestic violence as a child or adolescent (Evans, Davies, & DiLillo).

Two-thirds of American children and adolescents report experiencing trauma, with 33 percent of youth experiencing multiple traumas before reaching adulthood (Cohen & Mannarino, 2015). In a large epidemiological study of trauma and PTSD in youth, 68 percent of 16 year olds reported exposure to at least one traumatic event (Copeland, Keeler, Angold, & Costello, 2007). Of those, 37 percent reported exposure to multiple traumas and almost six percent reported exposure to at least one traumatic event in the last three months (Copeland, Keeler, Angold, & Costello). While shocking, this rate is consistent with the rate of trauma exposure reported in other studies (Green et al., 2000).

## **Consequences Associated with Trauma**

Experiencing trauma can lead to a broad range of potential psychological outcomes. However, it is important to note that, while the factors discussed in this section may be consequences of trauma, they do not always occur following trauma, and trauma is not a necessary precondition for psychopathology (APA, 2013). Additionally, exposure to trauma does not dictate later psychopathology; individual differences as well as risk factors influence the development of its symptoms.

Studies have shown, however, that trauma exposure is associated with increased risks of medical and mental health problems, including PTSD, depression, anxiety, substance abuse, and attempted and completed suicide (Cohen & Mannarino, 2015). The National Child and Traumatic Stress Network (NCTSN) found that many children exposed to trauma exhibit several forms of posttraumatic symptoms that "are not captured by standard PTSD, depressive, or anxiety disorder diagnoses" (2003). With more specific criteria for youths with PTSD symptoms, the prevalence rates may become more clear (APA, 2013). Specifically, 50 percent or more of the children surveyed who had been exposed to trauma exhibit difficulties in the domains of affect regulation, attention, concentration, negative self-image, impulse control, and

aggression/risk-taking (NCTSN). One-third of the children exposed to trauma exhibited problems with somatization (a process when mental and emotional stresses becoming physical), attachment, conduct disorder or oppositional defiant disorder, sexual interest/activity/avoidance, and/or dissociation (NCTSN). Childhood psychopathology related to trauma can manifest differently in children and adolescents than in adults. Children exposed to trauma exhibit a wide variety of symptoms and domains of impairment.

Children exposed to trauma also have an elevated risk for cognitive outcomes such as difficulties with attention, executive functioning, planning, and learning (NCTSN, 2003). Some children and adolescents exposed to trauma may exhibit physical or physiological differences. These difficulties may include hypersensitivity to physical contact, numbness, problems with coordination and balance, and somatization. Children and adolescents exposed to trauma are more prone to additional medical problems such as asthma, autoimmune disorders, and pseudoseizures (NCTSN). These youth may also exhibit a lack of sustained curiosity, have problems processing new information, have difficulties with language, and have impairments in auditory, visual, or spatial perception and comprehension (NCTSN). Children exposed to trauma may experience difficulties forming attachments and may have distrust of and/or uncertainty about those around them. This can lead to many other interpersonal difficulties, such as issues with setting appropriate boundaries (NCTSN).

Children and adolescents exposed to trauma may also experience negative outcomes related to emotion. Children may have difficulties with affect regulation, which may make it difficult for them to identify and describe feelings and internal experiences. They may also experience dissociative symptoms, such as depersonalization and derealization (i.e., alteration in the perception of the external world so that it seems unreal), and may even have amnesia for state-based events. Also, many youth exposed to trauma experience low self-esteem, shame or guilt, disturbances of body image, and/or lack of a predictable sense of self (NCTSN, 2003). Table 1 summarizes the potential difficulties children and adolescents may have after exposure to trauma.

The Adverse Childhood Experiences (ACE) study is one of the largest investigations ever conducted to assess associations between childhood maltreatment and its impact upon later-life health and well-being. The study was a collaboration between the Centers for Disease Control and Prevention (CDC) and Kaiser Permanente's Health Appraisal Clinic in San Diego (CDC, 2014). More than 17,000 Health Maintenance Organization (HMO) members underwent a comprehensive physical examination and provided detailed information about their childhood experience of abuse, neglect, and family dysfunction. The ACE study found that certain experiences are major risk factors and can be linked to illness and poor quality of life. These health and social problems arose because of adverse childhood experiences. The ACE study suggests the more traumatic experiences a youth has, the more likely they will have serious mental health issues when they are adults. According to the CDC, higher ACE scores are linked to serious social, cognitive, and physical impairments later in life. This study revealed the long-lasting effects of trauma.

Table 1
Summary of Potential Outcomes of Trauma in Children and Adolescents

Domain	Potential Difficulties	
Physical/ Physiological	<ul> <li>Hypersensitivity to physical contact</li> <li>Numbness</li> <li>Problems with coordination and balance</li> <li>Increased somatization</li> </ul>	
Medical	<ul> <li>Asthma</li> <li>Autoimmune disorders</li> <li>Pseudoseizures</li> <li>Sleep disturbances</li> <li>Disordered eating</li> </ul>	
Cognitive	<ul> <li>Attention</li> <li>Executive functioning</li> <li>Learning</li> <li>Lack of sustained curiosity</li> <li>Problems processing new information.</li> <li>Difficulties with language</li> <li>Impairments in auditory, visual, or spatial perception and comprehension</li> </ul>	
Attachment/ Relationships	<ul> <li>Distrust of and/or uncertainty about those around them</li> <li>Difficulties with boundaries</li> <li>Interpersonal difficulties</li> </ul>	
Behavioral	<ul> <li>Behavioral (impulse) control</li> <li>Self-destructive behavior</li> <li>Aggression</li> <li>Difficulty complying with rules</li> <li>Oppositional behavior</li> <li>Excessive compliance</li> </ul>	
Emotional	<ul> <li>Affect regulation</li> <li>Dissociative symptoms (e.g., depersonalization or derealization)</li> <li>Amnesia</li> <li>Low self-esteem</li> <li>Shame or guilt</li> <li>Disturbances of body image</li> <li>Lack of a predictable sense of self</li> </ul>	

Source: NCTSN, 2003.

## **Categories**

In addition to the many symptoms identified in previous sections, the *DSM-5* defines the disorders specifically related to trauma exposure. These diagnoses may be applied to both youth and adults if their behavior is consistent with the criteria set forth in the *DSM-5*. Table 2 provides a brief summary of these disorders.

#### Posttraumatic Stress Disorder (PTSD)

Children with PTSD show symptoms including, but not limited to, worrying about dying, insomnia, angry outbursts, and acting younger than their ages (AACAP, 2010). The manifestation of PTSD can be different in every child or adolescent (APA, 2013). Some youth experience PTSD through fear-based re-experiencing, while others have dysphoric mood states. PTSD can also manifest as arousal and reactive-externalizing symptoms (APA).

PTSD underwent some major changes in the *DSM-5*. For example, the criteria as to what constitutes a traumatic event are more explicit. The *DSM-5* also presents a wider range of what constitutes sexual violence. In addition, the individual's response to the event — intense fear, helplessness or horror, according to *DSM-IV* — has been deleted because that criterion proved to have no utility in predicting the onset of PTSD (APA, as cited by Grohol, 2013).

Instead of three major symptom clusters for PTSD, the *DSM-5* now lists four clusters:

- Recurrent experiences of the event, as in memories, dreams, or flashbacks;
- Amplified arousal, including sleep disturbances and reckless behavior;
- Avoiding thoughts, places, and memories about the event; and
- Negative thoughts, moods, or feelings (APA, 2013).

The *DSM-5* also included two new subtypes for PTSD. The first is PTSD Preschool Subtype, which is used to diagnose PTSD in children younger than six years of age. PTSD is also now developmentally sensitive, meaning that diagnostic thresholds have been lowered for children and adolescents (Grohol, 2013). The second new PTSD subtype is called PTSD Dissociative Subtype. This is diagnosed when PTSD is seen with prominent dissociative symptoms (Grohol). These dissociative symptoms can be either experiences of feeling detached from one's own mind or body, or experiences in which the world seems unreal, dreamlike, or distorted.

Children suffering from PTSD symptoms following a trauma should be treated quickly. The earlier the intervention, the more effective are the treatments (AACAP, 2010). The greatest emphasis should be placed on establishing an environment in which the child feels safe (AACAP). An evaluation by a child and adolescent psychiatrist should be sought for any child showing reoccurring problems handling a traumatic event.

Table 2

DSM-5 Disorders Affecting Children and Adolescents
Exposed to Trauma

Disorder		Description	
	PTSD	Re-experiencing, avoidance, and hyper-arousal symptoms following a traumatic event that are diagnosed at least four weeks after trauma exposure.	
Post- traumatic Stress Disorder (PTSD)	Preschool Subtype	Recreating trauma in play; ongoing dreams or nightmares related or unrelated to the traumatic event; avoiding activities or places that trigger memories of the trauma; and fear, guilt, and sadness, or withdrawing from friends and activities. Symptoms present for at least one month.	
	Dissociative Subtype	Symptoms of PTSD combined with depersonalization, ongoing feeling of detachment from the body or mind, and derealization (regularly feeling that one's surroundings are unreal, dreamlike, or distorted).	
Acute Stress (ASD)	Disorder	Dissociative, re-experiencing, avoidance, and hyper-arousal symptoms following a traumatic event that are diagnosed after lasting two days to four weeks after trauma.	
Adjustment Disorders		Emotional and behavioral symptoms in response to an identifiable stressor, such as termination of a relationship or a persistent painful illness.	
Disinhibited Social Engagement Disorder (DSED)		This disorder is diagnosed only in children. Children with DSED exhibit overly familiar and comfortable behavior with relative strangers.	
Reactive Attachment Disorder (RAD)		This disorder is diagnosed only in children. RAD affects infants and very young children. A child with RAD has a pattern of showing disturbed and developmentally inappropriate attachment behaviors. The child rarely or minimally turns to an attachment figure for comfosupport, protection, and nurturance.	
Other Trauma- and Stressor-Related Disorders		stressor_related disorder do not meet the full criteria for any of the	
Unspecified Trauma- and Stressor-Related Disorder		This category also applies when symptoms are characteristic of, but do not meet the full criteria for, any of the disorders included in the trauma- and stressor-related disorders diagnostic category. However, this category is used when the clinician chooses not to specify why the criteria are not met or there is insufficient information, such as during an emergency room visit.	

Source: APA, 2013.

## PTSD Preschool Subtype

The following bullet points outline the specific symptoms that are present with PTSD Preschool Subtype:

- Recreating trauma in play/recurrent dreams of the trauma;
- Ongoing nightmares with or without recognizable content about the traumatic event;
- Avoiding activities or places that remind the child of the trauma; and
- Exhibiting fear, guilt, and sadness, or withdrawing from friends and activities (APA, 2013).

These symptoms cause major distress to the child; impair relationships with parents, family members, and/or friends; and affect the child's behavior in school (APA, 2015).

## PTSD Dissociative Subtype

In addition to meeting PTSD diagnostic criteria, a child or adolescent with PTSD Dissociative Subtype must also have symptoms of either depersonalization or derealization (APA, 2013). Depersonalization is an ongoing feeling that the youth is detached from his or her body or mind. Derealization is the recurring experience that the youth's surroundings are unreal, dreamlike, or distorted (APA). There may be a link between childhood sexual abuse and dissociation that may help mediate psychiatric symptoms and risk-taking behaviors in this population (Ginzburg et al., 2006; Kisiel & Lyons, 2001).

#### Acute Stress Disorder (ASD)

According to the *DSM-5*, symptoms of ASD are experienced during or immediately after trauma and may last for a maximum of four weeks before the diagnosis must be reassessed. The duration of symptoms is at least three days, but no longer than four weeks (APA, 2013). If the symptoms persist past four weeks, the youth may be then diagnosed with PTSD if the criteria are met. However, a youth may be diagnosed with PTSD without having been previously diagnosed with ASD. Any symptoms manifesting immediately following the trauma that are resolved within three days do not meet the criteria for ASD (APA). The manifestation of the disorder differs in every individual, but typically consists of anxiety that includes some form of re-experiencing the trauma or reactivity related to the trauma (APA).

Approximately 50 percent of individuals with ASD may later develop PTSD (APA, 2015). Recognizing acute stress symptoms in children and adolescents is a critical first step in the path towards preventing PTSD.

#### Adjustment Disorders

Adjustment Disorders are emotional and behavioral symptoms in response to an identifiable stressor (APA, 2013). Examples of stressors include, but are not limited to, ending of a romantic relationship, persistent pain with increasing disability, living in a high-crime neighborhood, or experiencing a natural disaster (APA). The diagnosis should be reevaluated if the symptoms persist for more than six months following the termination of the stressor. The prevalence of adjustment disorders varies widely depending on the population studied (APA). Adjustment

disorders represent a simple response to some type of life stress, which may or may not be traumatic (Grohol, 2013).

Adjustment disorders are quite common in children and adolescents (Johns Hopkins Medicine, n.d.). For more information on Adjustment Disorders in youth, please refer to the Adjustment Disorders Section of the *Collection*.

#### Disinhibited Social Engagement Disorder (DSED)

Disinhibited Social Engagement Disorder (DSED) is a pattern of behavior in which a child exhibits inappropriately familiar behavior with strangers (APA, 2013). The disorder is symptomized by violations of normal social boundaries, such as reduced reticence in approaching and interacting with unfamiliar adults, unusually familiar behavior (verbal or physical), diminished checking with caregiver when venturing away in unfamiliar settings, or willingness to go off with unfamiliar adults (APA). DSED stems from extremely insufficient care of the child (APA). DSED is rare, even in children who have been severely neglected (APA). Lubit et al. (2013) outline the signs that suggest the presence of DSED. These signs include:

- Signs of physical maltreatment, undernutrition, and rashes;
- Excessive hunger and/or thirst;
- Flattened back of the head; and
- In the most severe cases, growth retardation.

Onset for DSED is typically before age five, and it may continue for life unless the child is treated and able to form new attachments (Lubit, et al.). Prevalence rates for DSED are not specifically known. However, in high-risk populations, including severely neglected children placed in foster care or institutions, approximately 20 percent exhibit signs of DSED (APA, 2013).

## Reactive Attachment Disorder (RAD)

RAD is characterized by a consistent pattern of emotionally withdrawn behavior by the child towards his or her caregiver (APA, 2013). A child with RAD rarely seeks comfort when distressed and rarely responds to comfort if given (APA). Children with RAD exhibit limited emotional responses, are often bewildered or confused, and have unexplained episodes of sadness and irritability. They may also be unhygienic and have underdeveloped motor coordination (APA; Lubit, et al., 2013). RAD stems from extremely insufficient care of the child (APA). RAD symptoms are very similar to those exhibited by children with Autism Spectrum Disorder, and children exhibiting these symptoms should be evaluated for both disorders. RAD is relatively rare and tends to occur in situations where a young child was exposed to neglect before being placed in foster care or in an institution (APA).

Prevalence rates for RAD are not specifically known. However, in high-risk populations, including severely neglected children placed in foster care or institutions, almost 10 percent exhibit signs of RAD (APA, 2013).

#### Other Trauma- and Stressor-Related Disorders

This category applies when symptoms are characteristic of, but do not meet the full criteria for, any of the disorders included in the trauma- and stressor-related disorders diagnostic category (APA, 2013). Examples of presentations that can be identified using this specification include the following:

- Adjustment-like disorders lasting more than six months without prolonged duration of the stressor;
- Adjustment-like disorder with delayed onset of symptoms that occur more than three or more months after the stressor;
- Ataque de nervios (attack of the nerves), a cultural syndrome among Latin Americans;
- Cultural syndromes; and
- Persistent complex bereavement characterized by severe and persistent grief and mourning reactions.

## Unspecified Trauma- and Stressor-Related Disorder

This category also applies when symptoms are characteristic of, but do not meet the full criteria for, any of the disorders included in the trauma- and stressor-related disorders diagnostic category (APA, 2013). However, this category is used when the clinician chooses not to specify why the criteria are not met for a specific disorder or there is insufficient information, such as in an emergency room setting (APA).

# Comorbidity

Children and adolescents exposed to trauma very often experience other kinds of problems. Those with ASD or PTSD may have symptoms of despair and hopelessness to the extent that they may meet criteria for a major depressive episode, and thus a major depressive disorder diagnosis may be more appropriate. Other youth with ASD or PTSD may experience guilt over their trauma, feeling as though they played a role. Some studies have found that as many as 75 percent of adolescents diagnosed with PTSD have at least one comorbid diagnosis of either major depressive episode or substance abuse/dependence (Kilpatrick et al., 2003). The *DSM-5* estimates that those with PTSD are more than 80 percent more likely to meet diagnostic criteria for one or more other mental disorders (APA, 2013). Studies have also shown that alcohol and other substances may be used to cope with symptoms of trauma-related anxiety (Jellinek, Patel, & Froehle, 2002). However, the use of substances can ultimately worsen symptoms and certain substances can actually generate anxiety symptoms. Another study of preschool-aged children with PTSD who had been exposed to Hurricane Katrina found that 89 percent had at least one comorbid disorder, with oppositional defiant disorder (ODD) and separation anxiety disorder (SAD) being the most common (Scheeringa & Zeanah, 2008).

Many of the behaviors seen in traumatized children fall in *DSM-5* diagnoses other than PTSD and ASD. Thus, discussions of comorbidity must be tempered with the knowledge that youth exposed to trauma may exhibit impairment across a broad range of domains, as discussed previously and outlined in Table 1.

#### Assessment

Early identification and treatment of traumatized children can prevent these potentially serious and long-term negative outcomes. Any attempt to define problematic posttraumatic stress in youth must clearly define what constitutes the more normal response to difficult events, loss, and trauma. Assessing the impact of trauma using current definitions of trauma may not properly screen for those children and adolescents who go on to develop psychopathology.

The suggested assessment tools for trauma- and stressor-related disorders are summarized in Table 3. Suggested assessment tools for PTSD are outlined in Table 4.

Not all children who are exposed to trauma are at equal risk for developing PTSD, and children may not meet full criteria for PTSD but may still have distressing and/or impairing symptoms. Accordingly, careful assessment is critical, as is knowledge of normal child development and normative reactions to difficult life events or trauma. One difficulty of assessment is the child's competence or inability to explain the trauma and the resulting psychosocial factors. Parental support and emotional state may affect a child's ability to properly report. Therefore, it is important to promote parental support for both assessment and treatment purposes (Kim, Choi, & Shin, 2011).

Since PTSD is often comorbid with other disorders, assessment typically involves asking about an array of potential problems. Assessment for PTSD in children should also include a medical history and a physical examination within the past 12 months, with special focus on conditions that may mimic PTSD or other anxiety disorders (AACAP, 2010). Assessing PTSD may require using multiple ways of gathering information in order to understand the youth's behavior across the many settings (e.g., school and home). Typically, questionnaires and interviews are used to assess for symptoms of PTSD. Some questionnaires that measure PTSD symptoms in children and adolescents over age seven are the UCLA PTSD Reaction Index, Child PTSD Symptom Scale (CPSS), and the Trauma Symptom Checklist for Children (TSCC) (AACAP). For children under age six, the PTSD for Preschool-Age Children is a checklist administered to caregivers to determine PTSD symptoms (AACAP).

These measures have moderate to strong psychometric profiles, but further expanded normative and clinical group studies of measures are needed (Hawkins & Randcliffe, 2006). However, these measures may be useful starting points for assessing symptoms. The PTSD Checklist/Parent Report, a parent-report measure, has been found to have strong psychometric properties (AACAP, 1998). However, when a parent or caregiver is an alleged perpetrator of child abuse or domestic violence, it is imperative that the clinician interview other caretakers (AACAP).

Table 3

Assessment for All Forms of Trauma- and Stressor-Related Disorders

Measure Type	Name of Measure	Who Completes	What is Learned
Symptom Checklist	Trauma Symptom Checklist for Children (TSCC)	Child/ Adolescent (ages 8-16 years)	Whether a child has acute and chronic posttraumatic symptoms; includes clinical scales and validity scales
Rating Scale	Adolescent-Dissociative Experiences Scale (A-DES)	Child	Presence of dissociation, especially associated with trauma-related distress
Checklist	Child Behavior Checklist and Youth Self-Report	Child, Parent or Teacher	Presence of symptoms including social withdrawal, somatic complaints, anxiety or depression, thought or attention problems, and behavior or aggression problems
Self-Report	Children's Depression Inventory (CDI)	Child	Presence of cognitive, affective, and behavioral signs of depression that signals a psychological response to trauma and perhaps an adjustment disorder
Rating Scale	Child Dissociative Checklist (CDC)	Parent	Presence of dissociative symptoms; children with trauma may score higher than children without
Checklist	Child Sexual Behavior Inventory (CSBI)	Parent	Assesses sexual behavior in children ages 2 - 12
Clinical Interview	Traumatic Events Screening Inventory	Clinician	Assesses the child's experience with traumatic events, including current and previous injuries, hospitalizations, domestic and/or community violence, disasters, accidents, and physical and/or sexual abuse

Sources: Hawkins & Radcliffe, 2006; Southam-Gerow & Chorpita, 2007; NCTSN, 2003; Muris, Merckelbach, & Peeters, 2003; & U.S. Department of Veterans Affairs, 2015.

Structured diagnostic interviews can be particularly helpful in assessing children, particularly when administered independently to the child and parent. When interviewing a child, it is important to use developmentally appropriate language. Two specifically strong diagnostic interviews are the Anxiety Disorders Interview Schedule for Children (ADIS-C) and the Schedule for Affective Disorders and Schizophrenia-Children's Present and Lifetime Version (K-SADS-PL). Both interviews have demonstrated strong psychometric characteristics for anxiety disorders (e.g., PTSD) across many studies (Hawkins & Radcliffe, 2006; Southam-Gerow & Chorpita, 2007). The ADIS-C includes a PTSD section and can be used with child and parent reports. In the K-SADS-PL, the clinician is asked to integrate parent and child reports, and initially asks whether a variety of traumatic events have occurred recently or in the past and then

assesses the criteria for a diagnosis of PTSD in relation to the specific event (Hawkins & Radcliffe). Additionally, the Clinician-Administered PTSD Scale for Children and Adolescents (CAPS-CA) is a semi-structured interview to assess PTSD symptoms in youth. This assessment tool was developmentally modified from an adult version (Hawkins & Radcliffe).

Table 4
Assessment for PTSD

Measure Type	Name of Measure	Who Completes	What Is Learned
Clinical Interview	Anxiety Disorders Interview Schedule – child (ADIS-C) and parent versions (ADIS-P)	Child, Parent	Whether a child meets criteria for PTSD
Clinical Interview	Schedule for Affective Disorders and Schizophrenia-Children's Present and Lifetime Version (K-SADS-PL)	Child, Parent	Whether a child meets criteria for PTSD
Clinical Interview	Clinician-Administered PTSD Scale for Children and Adolescents (CAPS-CA)	Child/ Adolescent (ages 7-15 years)	Whether the child has been exposed to trauma, overall symptom severity, and whether a current or lifetime diagnosis of PTSD/ASD is indicated
Rating Scale	UCLA PTSD Reaction Index (Child, Adolescent, and Parent versions)	Child, Adolescent, Parent	Whether a child has trauma exposure, PTSD symptoms (including duration of symptoms)
Rating Scale	Child PTSD Symptom Scale (CPSS)	Child/ Adolescent (ages 8-18 years)	Frequency of PTSD symptoms in children
Symptom Checklist	Trauma Symptom Checklist for Children (TSCC)	Child/ Adolescent (ages 8-16 years)	Whether a child has acute and chronic posttraumatic symptoms; includes clinical scales and validity scales
Symptom Checklist	PTSD Checklist – Child and Parent Report versions (PCL- C/PR)	Child/ Adolescent (ages 6-18), Parent	Whether child has symptoms of PTSD; measure does not assess for traumatic events or child functioning

Sources: Hawkins & Radcliffe, 2006; Southam-Gerow & Chorpita, 2007; NCTSN, 2003; Muris, Merckelbach, & Peeters, 2003; & U.S. Department of Veterans Affairs, 2015.

Youth who have experienced trauma within close relationships may have distrust and uncertainty about those around them, particularly if a trusted adult was a perpetrator (NCTSN, 2003). As such, these youth may resist disclosing information because they may fear additional family chaos and may also fear others will perceive them as peculiar. Moreover, youth may exhibit a

variety of outcomes after the exposure to trauma including comorbid symptoms. Some symptoms may be externalizing, such as behavior problems or aggression, and these overt symptoms may attract more clinical attention than internalizing symptoms (NCTSN). Finally, Hawkins and Radcliffe suggest that children who are exposed to a single traumatic event may be different in some ways than children who have been exposed to multiple traumatic events or prolonged stressors (NCTSN). Often, multiple traumas are not assessed, and symptom reporting relies on recalling the most recent traumas (Hawkins & Radcliffe).

#### **Treatments**

In the future, more evidence-supported treatments of disorders with *DSM-5* classifications will be available as clinical studies utilizing *DSM-5* criteria are conducted. As a result, this *Collection* will reference studies that utilize *DSM-IV* diagnostic criteria, primarily PTSD, to explain symptoms and treatments.

There are many treatments for PTSD; however, not all have been found to be equally effective. The efficacy of only one family of treatments has been studied thoroughly enough to declare it an evidence-based treatment: Trauma-Focused Cognitive Behavioral Therapy (TF-CBT). It is worth noting that TF-CBT has been tested and found to be more effective than other active treatments in treating childhood PTSD symptoms across six separate randomized clinical trials (Cohen & Mannarino, 2008).

Treatments for youth with PTSD are summarized in Table 5.

## Psychological Treatments

Trauma-Focused Cognitive Behavioral Therapy (TF-CBT) has been shown to be effective across a number of randomized controlled trials and to be more effective than other treatments (e.g., child-centered play therapy) at improving PTSD, as well as symptoms of depression, shame, and behavioral problems (Cohen, Deblinger, Mannarino, & Steer, 2004; Cohen, Kelleher & Mannarino, 2008; Cohen & Mannarino, 2015). Parents who participated in treatment with their children have also been shown to have improved parenting skills in addition to decreased levels of trauma distress and depression.

The TF-CBT model is based on cognitive and learning theories about the development of traumatic stress in youth, as well as information on effective interventions for adult PTSD and other child anxiety disorders (Cohen, Deblinger, Mannarino, & Steer, 2004). TF-CBT treatment includes core elements that make up the acronym PRACTICE (Cohen, Kelleher, & Mannarino, 2008). Each PRACTICE component builds on skills gained in previous sessions (Cohen, Deblinger, Mannarino, & Steer, 2004). The PRACTICE elements described by Cohen (2008) are as follows:

**P**sychoeducation provided to children and parents about trauma and PTSD symptoms, while parents are provided with parenting skills to aid in the management of the child's symptoms.

**R**elaxation skills are provided.

<u>Affective</u> expression and modulation skills are treatment components.

Cognitive coping skills are provided.

<u>Trauma narrative is developed and processed.</u>

<u>In-vivo</u> mastery of trauma reminders is introduced to differentiate between reminders and dangerous cues in the environment.

Conjoint sessions, where the child and parent focus on having the child share his or her narrative and working on family communication, are also included.

**E**nhancing safety focuses on safety planning in the future.

These components take 12 to 16 sessions (Cohen, Deblinger, Mannarino, & Steer, 2004). Similar to other cognitive-behavioral treatments, parent involvement and knowledge of skills are considered to be important components of treatment so that parents can help children with the skills outside of the therapy sessions.

TF-CBT is most effective with some degree of caregiver involvement (Getz, 2012); however, the treatment can still be effective with limited caregiver participation. Even in circumstances where there is no caregiver involvement, there is data that shows that PTSD improves with TF-CBT (Getz). TF-CBT may not be appropriate when the youth's predominant problems are disruptive behaviors such as defiance, disobedience, aggression, or rule breaking (Child Sexual Abuse Task Force and Research & Practice Core, NCTSN, 2004). Similarly, children who are severely depressed or suicidal, or who have active substance abuse, should first receive treatments specific to those conditions. TF-CBT will often be an appropriate intervention for these children once the above presenting problems have been addressed (Getz).

Although TF-CBT has the most research support, school-based group Cognitive Behavioral Therapy (CBT) has shown some promise in a few studies (Cohen, Kelleher, & Mannarino, 2008; Silverman et al., 2008). School-based group CBT uses PRACTICE components similar to TF-CBT. All elements, except for the individual activity of a trauma narrative, are provided in a group format with parents rarely becoming involved. There is also a teacher education component and peer support component (Cohen, Kelleher, & Mannarino).

For RAD and DSED, treatments have been shown to be beneficial when they emphasize the following in the child/caregiver relationship: psychological safety, stability in the time spent with the child, empathy when listening, permanence of an attachment figure, and emotional availability or attentiveness to the child's needs (Lubit, et al., 2013). A child with RAD or DSED may take a year or longer to trust a caregiver again (Lubit, et al.).

Table 5
Summary of Treatments for Youth with PTSD

What Works	
Trauma-Focused Cognitive Behavioral Therapy (TF-CBT)	Treatment that involves reducing negative emotional and behavioral responses related to trauma by providing psychoeducation on trauma, addressing distorted beliefs and attributes related to trauma, introducing relaxation and stress management techniques, and developing a trauma narrative in a supportive environment
What Seems to Work	
School-based Group Cognitive Behavioral Therapy (CBT)	Similar components to TF-CBT, but in a group, school-based format
Not Adequately Tested	
Child-centered Play Therapy	Therapy that utilizes child-centered play to encourage expression of feelings and healing
Psychological Debriefing	An approach in which youth talk about the facts of the trauma (and associated thoughts and feelings) and then are encouraged to re-enter into the present
Pharmacological Treatments	Treatment with selective serotonin reuptake inhibitors (SSRIs)
Resilient Peer Treatment	Classroom treatment that pairs withdrawn children with resilient peers with a parent present for assistance
Eye Movement Desensitization and Reprocessing Therapy (EMDR)	Therapy that utilizes visual and physical memory imagery while the clinician creates visual or auditory stimulus to reduce negative memory and increase positive memory
What Does Not Work	
Restrictive rebirthing or holding techniques	Restrictive rebirthing or holding techniques that may forcibly bind or restrict, coerce, or withhold food/water from children and have resulted, in some cases, in death; not recommended

## Pharmacological Treatments

While pharmacological treatments (e.g., selective serotonin reuptake inhibitors [SSRIs]) have been found to be useful in treating other anxiety disorders, there is inadequate support for pharmacological interventions in the treatment of PTSD (AACAP, 1998). One study examined the effects of adding the SSRI sertraline to a TF-CBT intervention for PTSD and found that there was minimal evidence of benefit (Cohen, Mannarino, Perel, & Staron, 2007). SSRIs may not be optimal for treatment for children with PTSD who also have hyperarousal symptoms, as SSRIs

may lead to irritability, poor sleep, or inattention in some children (AACAP, 2010). For these children, alternative therapy should be considered, including TF-CBT or alternative psychotropic medications (AACAP). Research has shown that employing TF-CBT to treat PTSD prior to adding medication is warranted. In general, if a youth with PTSD is also diagnosed with depression, anxiety, panic and/or ADHD symptoms, clinicians who treat with medication are urged to choose medications based on the evidence for treating the comorbid condition (AACAP, 1998).

#### Trauma-Informed Care

A new form of care is emerging that takes into consideration trauma that individuals experienced in the past. Trauma-informed care programs are based on recognition that trauma survivors are vulnerable and potentially have triggers that may be aggravated by traditional service approaches. These programs seek to avoid those triggers and to prevent the trauma from reoccurring (Substance Abuse and Mental Health Services Administration [SAMHSA], n.d.). The treatments under trauma-informed care mirror those for PTSD, including TF-CBT (NCTSN, n.d.). Because nearly half of all children have had an experience that can be classified as a traumatic experience, trauma-informed care is appropriate because it avoids situations wherein undo stress is placed upon a child by no fault of the clinician (Johns Hopkins Bloomberg School of Public Health, 2014). These triggers are thought to have a negative effect on an affected youth's cognitive performance in the short term as well as long-term effects on physical and cognitive health (Bethell, Newacheck, Hawes, & Halfon, 2014).

#### **Unproven Treatments**

There are many treatments for PTSD that have not yet been tested and others that have no research to support their effectiveness. Moreover, some treatments that have been studied have been found to be less effective, not effective, or harmful in treating children with PTSD (Cohen, Kelleher, & Mannarino, 2008). One intervention, psychological de-briefing, in which children are encouraged to talk about the trauma, as well as their thoughts and feelings, before re-entering into the present, has been studied and found to have no significant effects (Cohen, Kelleher, & Mannarino). Nondirective, or child-directed, play and other unstructured treatment approaches are less effective in treating effects of trauma than TF-CBT (Cohen, Kelleher, & Mannarino). Other treatments, such as restrictive rebirthing or holding techniques, have been found to be harmful to children and should not be used (Cohen, Kelleher, & Mannarino).

#### **Cultural Considerations**

The understanding of trauma and its outcomes may vary significantly from culture to culture. For instance, Latino children may experience a symptom known as *susto*, meaning "fright" or "soul loss" (APA, 2000). *Susto* can occur following a frightening event and may impact social relationships, appetite, and sleep; enhance feelings of sadness; decrease motivation; and increase feelings of worthlessness (APA).

Research suggests that providers address cultural issues directly with the parents and, if appropriate, with the child they are treating (Cohen, Mannarino & Deblinger, 2006). It is important for therapists to recognize that painful and distressing responses to trauma are universal, even if the specific symptoms vary to some extent from culture to culture (Cohen,

Mannarino, & Deblinger). Furthermore, although therapists are not able to change their own cultural background, they can learn about and be respectful of other cultural reactions to traumatic experiences while providing effective psychological treatment for trauma-related psychopathology (Cohen, Mannarino, & Deblinger). As of 2008, TF-CBT treatment materials have been translated into Spanish, Dutch, and German (Cohen, Kelleher, & Mannarino, 2008). TF-CBT is also being culturally adapted for use with African children impacted by human immunodeficiency virus (HIV) (Cohen, Kelleher, & Mannarino).

The information in the following paragraph is derived from the Jim Casey Youth Opportunities Initiative (2011). Many youth in foster care have also experienced traumatic events in their lives due to exposure to psychological or physical abuse, neglect, and dislocation. Researchers and service providers have concluded that the great majority of young people in foster care have experienced trauma in some form as a result of maltreatment and foster care placement. Data from the National Survey of Child and Adolescent Well-Being indicate that high percentages of the caregivers whose children have entered foster care also experience significant stressors in their lives that, in turn, affect the psychological well-being of their children. The foster care experience itself may cumulatively add to the impact of these traumatic events by further traumatizing young people. In addition, because they are removed from family, school, and community, multiple placements contribute to the loss of important relationships and bonds, and youth in foster care are frequently uncertain whether parents, siblings, former caregivers, or friends will return to their lives. This type of ambiguous loss freezes the grief process, prevents closure, and adds to young people's feelings of insecurity and confusion.

#### **Overview for Families**

Children and adolescents experience stressful events, and they may have physical and emotional reactions to the stress. Certain events are more likely to trigger PTSD, including being the victim of or witness to physical or sexual abuse, violence, accidents, and natural disasters, or being diagnosed with a life threatening illness (AACAP, 2011a).

After traumatic events, children may first be angry or confused. If they are repeatedly exposed to an event, they may block or deaden the emotional pain they feel. This process is called dissociation (AACAP, 2011a). Children may also avoid situations or places that remind them of the trauma (APA, 2013). Families may also notice that children have who experienced trauma are less emotionally responsive, more depressed or withdrawn, or even detached from their feelings (AACAP).

Sometimes children with PTSD will experience symptoms like recurring memories and bad dreams. Children may even reenact the traumatic event during play. These after effects may elicit similar feelings as those experienced during the traumatic event (AACAP, 2011a). Families should look for the following symptoms:

- Fear of dying early
- Loss of interest in activities
- Physical symptoms like headaches and bellyaches
- Sudden and extreme emotional reactions
- Problems sleeping, both in falling and staying asleep
- Irritability or angry outbursts
- Trouble concentrating
- Acting younger than their age, including thumb sucking, whining, and clinging to an adult
- Increased awareness or alertness to their surroundings
- Repeating behavior that reminds them of the trauma (AACAP, 2011a)

These symptoms may last for months or even years. If a traumatic event occurs, it is best for the family to seek help from a trained clinician as soon as possible.

Young children under age six who experience trauma may recreate trauma in their play (Kids Matter Early Childhood, n.d.). Families should pay attention to the play of a child who is suspected to have experienced trauma, as that may be the only way the child can explain his or her feelings to the family. This is often because the child's speech and vocabulary are still developing (Kids Matter Early Childhood).

Families can work together with clinicians to create a sense of safety. Therapy where the child can speak, draw, play, or write about the traumatic event will help, and behavior modification may reduce the fear and worry associated with the trauma (AACAP, 2011a).

Another disorder that families may experience after trauma is reactive attachment disorder (RAD). Children with RAD seem detached from or unresponsive to their families (AACAP, 2011b). Symptoms typically occur around age five, but may occur in infants and continue as the child ages. Parents usually notice some or all of the following symptoms:

- Severe colic or difficulties feeding
- Failure to gain weight appropriately
- Difficulty comforting the child
- A preoccupied or defiant attitude
- Being inhibited or hesitant in social interactions
- Being disinhibited or inappropriately familiar with strangers (AACAP, 2011b)

Frequently, these symptoms occur in children who have been physically or emotionally abused or even neglected. Often, RAD occurs in children raised in hospitals or institutional settings, those who have experienced traumatic loss, or those whose primary caregiver changes frequently (AACAP, 2011b). Children who receive inadequate care are most at risk for RAD. Treatment involves the child and the family. Families who suspect RAD in a child should reach out to a clinician for assistance.

## **Resources and Organizations**

#### **Anxiety Disorders Association of America (ADAA)**

8730 Georgia Avenue, Suite 600 – Silver Spring, MD 20910 https://adaa.org/

## Child Welfare League of America (CWLA)

440 First Street NW, Third Floor – Washington, DC 20001-2085 http://www.cwla.org

# Georgetown University Center for Child and Human Development

Trauma Informed Care

http://gucchdtacenter.georgetown.edu/TraumaInformedCare.html

## **International Society for Traumatic Stress Studies (ISTSS)**

111 Deer Lake Road, Suite 100 – Deerfield, IL 60015 http://www.istss.org/

## **Medical University of South Carolina (MUSC)**

Trauma Focused-Cognitive Behavioral Therapy http://tfcbt.musc.edu

#### **National Anxiety Foundation**

3135 Custer Drive – Lexington, KY 40517 http://www.nationalanxietyfoundation.org/

#### **National Center for Trauma Informed Care**

https://www.samhsa.gov/nctic/about

#### **National Child Traumatic Stress Network**

http://www.nctsnet.org/

#### **Prevent Child Abuse America**

228 S. Wabash Avenue, 10 FL – Chicago, IL 60604 800-CHILDREN (244-5373) or 312-663-3520 http://preventchildabuse.org/

## Virginia Resources and Organizations

## Child Savers Guidance Clinic & Trauma Response

200 North 22nd Street – Richmond, VA 23223 804-644-9590 (*Ask for a Trauma Response therapist, if applicable.*) https://childsavers.org/

## **Prevent Child Abuse Virginia**

4901 Fitzhugh Avenue, Suite 200 – Richmond, VA 23230 E-mail: jschuchert@pcav.org
http://pcav.org/

## **University of Virginia Health System**

Children's Hospital

https://childrens.uvahealth.com/

## Virginia Commonwealth University (VCU)

Center for Psychological Services and Development https://cpsd.vcu.edu/

## **VCU Medical Center**

Virginia Treatment Center for Children

https://www.chrichmond.org/Services/Mental-and-Behavioral-Health.htm?vtcc=true

## Virginia Department of Behavioral Health Services

http://www.dbhds.virginia.gov/

Trauma Informed Care

 $http://www.dbhds.virginia.gov/developmental-services/children-and-families/Trauma\%\,20Informed\%\,20Care$ 

## **Virginia Polytechnic Institute and State University (VA Tech)**

Psychological Services Center

http://www.psyc.vt.edu/outreach/psc

Child Study Center

http://www.psyc.vt.edu/labs/csc

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# ADJUSTMENT DISORDER

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### Introduction

An adjustment disorder is an unhealthy behavioral response to a stressful event or circumstance (Medical Center of Central Georgia, 2002). Youth who experience distress in excess of what is an expected response may experience significant impairment in normal daily functioning and activities (Institute for Health, Health Care Policy and Aging Research, 2002).

Adjustment disorders in youth are created by factors similar to those in adults. Factors that may contribute to the development of adjustment disorders include the nature of the stressor and the vulnerabilities of the child, as well as other intrinsic and extrinsic factors (Benton & Lynch, 2009). In order to be diagnosed as an adjustment disorder, the child's reaction must occur within three months of the identified event (Medical Center of Central Georgia, 2002). Typically, the symptoms do not last more than six months, and the majority of children quickly return to normal functioning (United Behavioral Health, 2002). Adjustment disorders differ from post-traumatic stress disorder (PTSD) in that PTSD usually occurs in reaction to a life-threatening event and may last longer (Access Med Health Library, 2002). Adjustment disorders may be difficult to distinguish from major depressive disorder (Casey & Doherty, 2012).

Unless otherwise cited, the following information is attributed to the University of Chicago Comer Children's Hospital (2005). In clinical samples of children and adolescents, males and females are equally likely to be diagnosed with an adjustment disorder (American Psychiatric Association [APA], 2000). Adjustment disorders occur at all ages. However, characteristics of the disorder in children and adolescents are different from those in adults. Differences are noted in the symptoms experienced, in the severity and duration of symptoms, and in outcomes. Adolescent symptoms of adjustment disorders are more behavioral (for instance, acting out), while adults experience more depressive symptoms.

## Recent Changes from the DSM-IV to the DSM-5

The *DSM-5* is a manual for assessment and diagnosis of mental health disorders and does not include information for treatment of any disorder. In the future, more evidence supporting treatments of disorders with *DSM-5* classifications will be available as clinical studies utilizing *DSM-5* criteria are conducted. As a result, this *Collection* will reference studies that utilize *DSM-IV* diagnostic criteria to explain symptoms and treatments.

Adjustment disorders are part of the Trauma and Stressor-Related Disorders section of the *DSM-5*. In the *DSM-IV*, adjustment disorders were characterized as clinically significant distress not categorized by another disorder. The *DSM-5* recategorizes adjustment disorders as a "heterogeneous array of stress response syndromes that occur after exposure to a distressing (traumatic or nontraumatic) event" (American Psychiatric Association [APA], 2013).

### **Prevalence**

Adjustment disorder prevalence varies depending upon the population studied and the method used in that study. Of individuals undergoing outpatient mental health care treatment, 5 to 20 percent are diagnosed with an adjustment disorder. Individuals in a psychiatric hospital setting have a prevalence rate as high as 50 percent (APA, 2013). This data represents individuals of all ages. At this time, there are no official figures representing prevalence rates in youth. However, in 1997, the U.S. Department of Health and Human Services, the Substance Abuse and Mental Health Service Administration (SAMHSA), and the Center for Mental Health Services conducted a client/patient sample survey of 8,000 children in mental health facilities. These children were randomly selected and surveyed in order to calculate national estimates of mental health services. The findings of the study indicated that 16 percent of the children who were admitted had an adjustment disorder (Institute for Health, Health Care Policy and Aging Research, 2002).

### Causes and Risk Factors

Adjustment disorders are a behavioral or emotional reaction to an outside stressor. Because children possess varying dispositions, as well as different vulnerabilities and coping skills, it is impossible to attribute a single explanation as to why some stressors trigger adjustment disorders in some children and others do not (Medical Center of Central Georgia, 2002). However, experts have found that the developmental stage of the child and the strength of the child's support system influence their reaction to the stressor (Medical Center of Central Georgia). One common trigger for adjustment disorder includes grief and bereavement, especially following the death of a family member or sibling (Machajewski & Kronk, 2013). There is no evidence to indicate that biological factors influence the cause of adjustment disorders; the most widely accepted thought is that stress itself is the precipitating factor (Benton & Lynch, 2009).

According to Benton and Lynch (2009), an important factor in the development of an adjustment disorder is the vulnerability of the child. Vulnerability depends on the characteristics of both the child and the child's environment. The *DSM-5* notes that individuals in "disadvantaged life circumstances" experience a high stressor rate and, as a result, may be at greater risk for developing adjustment disorders (APA, 2013).

### Classifications

According to the University of Chicago Comer Children's Hospital (2005), in adjustment disorders, a child's reaction to the stressor is beyond a normal reaction or significantly interferes with social, occupational, or educational functioning. In adults, there are six subtypes of adjustment disorder, based on the major symptoms experienced. However, clinical symptoms in children and adolescents differ from those in adults (Benton & Lynch, 2009), and there may be a predominance of mixed, rather than discrete, symptom presentations (Newcorn & Strain, 1992). Research has also suggested that more serious mental health disorders were present in children and adolescents after five years of follow-up (Andreasen & Hoenk, as cited by Benton & Lynch).

Table 1
Adjustment Disorder Subtypes

Subtype	Key Characteristics	Symptoms
With depressed mood	Symptoms are that of a minor depression	Depressed mood; tearfulness; feelings of hopelessness
With anxiety	Symptoms of anxiety are dominant	Nervousness; worry; jitteriness; fear of separation from major attachment figures
With depressed mood and anxiety	Symptoms are a combination of depression and anxiety	Combination of symptoms from both the above subtypes
With disturbance of conduct	Symptoms are demonstrated in behaviors that break societal norms or violate the rights others	Violation of the rights of others and/or societal norms and rules; truancy; destruction of property; reckless driving; fighting
With mixed disturbance of emotions and conduct	Symptoms include combined affective and behavioral characteristics with mixed emotional features and a disturbance of conduct	Combination with depressed mood and anxiety and with disturbances of conduct
Unspecified	Maladaptive reaction is not classified under other adjustment disorders but occurs in response to stress	Reactions to stress that do not fit into other subtypes

Source: APA, 2013.

# Diagnosis

Because most features of adjustment disorders (such as the stressor, the maladaptive reaction, the accompanying mood and feature, and the time and relationship between the stressor and the response) are subjective, these disorders can be particularly difficult to diagnose (Benton & Lynch, 2009). The *DSM-5* has specific diagnostic criteria in order to properly diagnose individuals with an adjustment disorder. These criteria include:

- Emotional or behavioral symptoms that are in response to an external stressor;
- Stress that is un-proportional to the stressor;
- Stress-related symptoms do not meet the criteria for another disorder; and
- Symptoms do not last longer than six months after stressor is removed (APA, 2013).

A qualified mental health professional should assess a child suspected of having an adjustment disorder following a comprehensive psychiatric evaluation and interview with the child and the family (Medical Center of Central Georgia, 2002; Carta, Balestrieri, Murru, & Hardoy, 2009). Specifically, a personal history appraising development, life events, emotions, behaviors, and the identified stressful event should be performed during the assessment process in order to correctly diagnose the adjustment disorder (Medical Center of Central Georgia). Figure 1 outlines the characteristics of adjustment disorders.

# Figure 1

## **Characteristics of Adjustment Disorders**

- Disorders occur equally in males and females
- Stressors and symptoms may vary, depending on cultural influences
- Characteristics in children differ from those in adults
- Symptoms in adolescents are more behavioral; symptoms in adults are more depressive

Source: Medical Center of Central Georgia, 2002.

# Comorbidity

Adjustment disorders can occur with many different mental disorders and any medical disorders. As many as 70 percent of all individuals diagnosed with an adjustment disorder are also diagnosed with a comorbid disorder or illness (APA, 2013; Frank, 2014). Adjustment disorders can be diagnosed at the same time as other mental disorders as long as the comorbid diagnosis does not account for the symptoms experienced by the individual being diagnosed (APA). Oftentimes, adjustment disorders are diagnosed correspondingly to medical illness because medical illness may cause a major psychological response (APA). In children, adjustment disorders are also most likely to occur with conduct or behavioral problems (Woo, 2003). Patients with adjustment disorders may engage in deliberate self-harm at a rate that surpasses abuse disorders (Benton & Lynch). More studies are needed to focus on the association between adjustment disorders and other mental disorders, including substance abuse disorders.

### **Treatment**

Because an adjustment disorder is a psychological reaction to a stressor, the most widely accepted treatment process involves identifying the stressor and having a child communicate that stressor effectively. The child can then attempt to move past their stressor and subsequent relatable problems (Benton & Lynch, 2009). If the stressor is eliminated, reduced, or accommodated, the child's maladaptive response can also be reduced or eliminated.

Accordingly, treatment of adjustment disorder usually involves psychotherapy that seeks to reduce or remove the stressor or improve coping ability (Strain, as cited by Benton & Lynch).

Treatments for adjustment disorders must be tailored to the needs of the child, based on the child's age, health, and medical history (Medical Center of Central Georgia, 2002). There is no consensus on a clear treatment plan at this time. Treatment selection is a clinical decision to be made with the treating clinician and the patient. However, because of the brevity of adjustment disorders, short-term psychotherapy is generally preferred to long-term (Frank, 2014).

Treatments are discussed in the paragraphs that follow and are outlined in Table 2.

Table 2
Summary of Treatments for Adjustment Disorder

What Works		
There are no evidence-based practices at this time.		
What Seems to Work		
Interpersonal psychotherapy (IPT)	IPT helps children and adolescents address problems to relieve depressive symptoms.	
Cognitive behavioral therapy (CBT)	CBT is used to improve age-appropriate problem-solving skills, communication skills, and stress management skills. It also helps the child's emotional state and support systems to enhance adaptation and coping.	
Stress management	Stress management is particularly beneficial in cases of high stress and helps the youth learn how to manage stress in a healthy way.	
Group therapy	Group therapy among of likeminded/afflicted individuals can help group members cope with various features of adjustment disorders.	
Family therapy	Family therapy is helpful for identifying needed changes within the family system. These changes may include improving communication skills and family interactions and increasing support among family members.	
What Does Not Work		
Pharmacology alone	Medication is seldom used as a singular treatment because it does not provide assistance to the child in learning how to cope with the stressor.	

Sources: Citations provided in text.

# **Psychotherapy**

Psychotherapy is the treatment of choice for adjustment disorders because the symptoms are a direct reaction to a specific stressor (Turkington, 1995). However, the type of therapy depends on the needs of the child, with the focus being on addressing the stressors and working to resolve the problem. Interpersonal psychotherapy (IPT) has the most support for treating children with

adjustment disorders (Society of Clinical Child and Adolescent Psychology, 2006). For depressed adolescents, IPT is a well-established treatment (Mufson et al., 2004). IPT helps children and adolescents address problems in their relationships with family members and friends (Society of Clinical Child and Adolescent Psychology). Typically, the clinician works one-on-one with the child and his or her family. One study reported that adolescents who participated in IPT had significant reductions in their depressive symptoms and noted improvements in their social functioning (Mufson et al.). The largest improvement was noted in older and more severely depressed adolescents (Mufson et al.).

Within preliminary clinical trials, brief treatment using cognitive-behavioral strategies also shows promise (Society of Clinical Child and Adolescent Psychology, 2006). Cognitive-behavioral approaches are used to improve age-appropriate problem solving skills, communication skills, impulse control, anger management skills, and stress management skills (Medical Center of Central Georgia, 2002). Additionally, therapy assists with shaping an emotional state and support systems to enhance adaptation and coping (Benton & Lynch, 2009).

There are specific goals that should be met during psychotherapy in order for it to be successful for the patient. During psychotherapy the following should occur:

- Analyze stressors affecting patient;
- Clarify and interpret the meaning of the stressor;
- Attempt to reframe stressor;
- Illuminate concerns of the patient;
- Configure a plan to reduce stressor; and
- Increase coping skills of patient (Frank, 2014).

Stress management and group therapy are particularly beneficial in cases of work-related and/or family stress. Family therapy is frequently utilized, with the focus on making needed changes within the family system. These changes may include improving communication skills and family interactions and increasing support among family members (Medical Center of Central Georgia, 2002).

Preventive measures to reduce the incidence of adjustment disorders in children are not known at this time. However, early detection and intervention can reduce the severity of symptoms, enhance the child's normal growth and development, and improve quality of life (University of Chicago Comer Children's Hospital, 2005).

# Pharmacological Treatment

Medication is seldom used as a single treatment for adjustment disorders because the child requires assistance in coping with the stressor, as well as his or her reaction to it. However, targeted symptomatic treatment of the anxiety, depression, and insomnia that can occur with adjustment disorders may effectively augment therapy, but is not recommended as the primary treatment for adjustment disorders (Frank, 2014). As cited in Benton & Lynch (2009), in a retrospective study of 72 adolescents diagnosed with adjustment disorder, researchers Ansari and Matar posited that disappointment in relationships was the primary stressor causing the disorder.

Accordingly, the symptoms of the disorder must be addressed through psychotherapy, rather than pharmacology.

While pharmacological measures may not be the most desired option when treating adjustment disorders, a few accepted treatment options are outlined below:

- Benzodiazepines (lorazepam or clorazepate)
- Selective serotonin reuptake inhibitors (SSRIs) or serotonin—norepinephrine reuptake inhibitors (SNRIs) (sertaline or venlafaxine)
- Plant extracts (kava kava or valerian) (Frank, 2014)

In addition, short-term use of anxiolytics and hypnotics may be beneficial.

Some research findings also suggest that SSRIs may help relieve depressive symptoms, especially in adolescents (Society of Clinical Child and Adolescent Psychology, 2006). A more detailed discussion of the use of antidepressants in treating children and adolescents is included in the "Antidepressants and the Risk of Suicidal Behavior" section of the *Collection*.

### **Cultural Considerations**

Adjustment disorders are likely to be seen across cultures without variation based on race or ethnicity (Gau, Chong, Chen, & Cheng, 2005). Migration, immigration, or otherwise moving may increase the likelihood of adjustment disorders in youth (Barrett, Turner, & Sonderegger, 2000; Refugee Health Technical Assistance Center, 2011). While not specific to adjustment disorders, a positive ethnic or racial identity is tied to psychosocial functioning, academic adjustment, and fewer risky behaviors among adolescents of color (Rivas-Drake et al., 2014). This may be important to prevent adjustment disorders or ease their effects.

### **Overview for Families**

Adjustment disorders occur when a youth finds it difficult to cope with a stressful event or situation. Mental and physical symptoms of adjustment disorders include:

- Stress
- Feeling sad or hopeless; crying or withdrawing from others
- Defiant or impulsive behavior, including vandalism and ignoring school work
- Nervous or tense demeanor
- Arrhythmia (skipped heartbeats), twitching, trembling, or other physical symptoms (Rogge, 2013; Mayo Clinic, 2011)

This list is not exhaustive, but it may help determine whether a physical or emotional symptom is in reaction to a stressor. The symptoms must appear soon after a stressor, be more severe than expected, not be part of another disorder, and not have any other reasonable explanation (Rogge, 2013). Families should take care, as thoughts or attempts of suicide may occur with adjustment disorders (Mayo Clinic, 2011).

Stressors that may cause adjustment disorders can include the following:

- Death of a loved one
- Illness in the youth or a family member
- Moving to a different home or a different environment
- Unexpected catastrophes, including natural disasters
- Family problems
- School problems
- Sexuality issues (Rogge, 2013)

Not every individual will develop an adjustment disorder after one or several of these life events. Better social skills and coping techniques may help prevent adjustment disorders (Rogge, 2013).

Children and adolescents can work with clinicians to overcome the symptoms of adjustment disorders. Often, the treatment will include talk therapy to help identify and even change the stressors in the child's life. One type of therapy is cognitive behavioral therapy (CBT) wherein the therapist will help the youth identify negative feelings and thoughts and then show them how to change those thoughts into healthy, positive thoughts and actions (Rogge, 2013).

Families can also utilize the following techniques to help reduce stress:

- Allow your child to talk about the stress in a supportive environment
- Eat a healthy diet
- Have a regular sleep routine
- Get regular physical activity
- Engage in a hobby, either alone or with family
- Offer support and understanding
- Reassure your child that his or her reactions are common
- Work with teachers to track progress at school
- Let your child make simple decisions, including dinner and movie choices (Mayo Clinic, 2011)

## **Resources and Organizations**

## American Academy of Child Adolescent Psychiatry (AACAP)

http://www.aacap.org/

## **Child Welfare Information Gateway**

https://www.childwelfare.gov/

### **Internet Mental Health**

http://www.mentalhealth.com/home/

#### **Mental Health Matters**

https://mental-health-matters.com/

## **New York University School of Medicine**

Child Study Center

https://med.nyu.edu/child-adolescent-psychiatry/

## U.S. Department of Health and Human Services

https://www.hhs.gov/

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# EEDING AND EATING DISORDERS

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### Introduction

Eating disorders are a significant problem in the United States among children and adolescents of all ethnic groups (Nicholls & Viner, 2005). The incidence of eating disorders among adolescent females has grown at an alarming rate over the past several decades (American Dietetic Association [ADA], 2001). The American Psychiatric Association (APA) has reported that eating disorders are now the third most common form of chronic illness in the adolescent female population (2000), with prevalence rates as high as ten percent (American Academy of Child and Adolescent Psychiatry [AACAP], 2013). Males also struggle with eating disorders, as they account for approximately 10 percent of the bulimia nervosa population and 35 percent of the anorexia nervosa population (APA, 2013, Anorexia Nervosa and Related Eating Disorders, Inc. [ANRED], 2004; Spitzer et al., 1993).

Although anorexia nervosa (AN) predominantly affects adolescent and young adult females, there are reports of children as young as six years of age affected by the disorder (ANRED, 2004). Similarly, bulimia nervosa (BN) generally affects adolescents, although there have been cases reported for children much younger (International Eating Disorder Referral Organization, n.d.). A recent assessment of eating disorder trends in London suggests that the number of young adult females with the diagnoses of AN has stabilized and the number of reported BN diagnoses has decreased (Currin et al., 2005). However, this is not the case for adolescents, as incidence rates for AN continue to rise (Herpertz-Dahlmann, 2008). A further telling statistic is the fact that only 10 percent of diagnosable individuals actually receive treatment for their disorder (Eating Disorders Coalition [EDC], n.d.). AN has the highest mortality rate of any mental health disorder (Hoek, 2006). It is important to note that there is significant variance on the reported

number of deaths because these individuals may ultimately die from serious medical complications associated with feeding and eating disorders.

## Recent Changes from the DSM-IV to the DSM-5

In 2013, the American Psychiatric Association released the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*). The *DSM-5* introduced a chapter titled "Feeding and Eating Disorders," which takes a life-span approach to diagnosing eating disorders and contains all related diagnoses (Kenny, Ward-Lichterman, & Abdelmonem, 2014). Disorders now included in this category are pica and rumination and avoidant/restrictive food intake disorder. Additionally, the *DSM-5* recognizes binge-eating disorder (BED) as an official disorder. While pica and rumination disorder remain unchanged, AN and BN experienced some criteria changes. The *DSM-5* also includes a system for classifying the severity of several eating disorders (mild, moderate, and severe) and attempts to address the number of cases of eating disorders that do not meet criteria.

The *DSM-5* is a manual for assessment and diagnosis of mental health disorders and does not include information for treatment of any disorder. In the future, more evidence supporting treatments of disorders with *DSM-5* classifications will be available as clinical studies utilizing *DSM-5* criteria are conducted. As a result, this *Collection* will reference studies that utilize *DSM-IV* diagnostic criteria to explain symptoms and treatments.

This section of the *Collection* will focus on the three most prevalent eating disorders that affect children and adolescents; AN, BN, and Binge-eating Disorder (BED). This is because the prevalence rates of the other Feeding and Eating Disorders are unclear and two of the classifications are more likely to be present with a comorbid intellectual disability (APA, 2013).

Table 1 outlines the changes to the "Feeding and Eating Disorders" classification.

## **Categories**

This section describes the three most prevalent eating disorders that affect youth: anorexia nervosa, bulimia nervosa, and binge-eating disorder.

### Anorexia Nervosa (AN)

The primary characteristic/criterion of AN is intense fear of gaining weight or becoming fat, even when the individual is underweight. Individuals with AN resists maintaining their body weight at or above a minimally normal weight for their age and height. Youth with AN will often exhibit "significantly low weight," which is defined as weighing less than what is minimally expected (APA, 2013). The APA (2013) outlines the likely symptoms of youth having AN. These symptoms include:

- Disturbance in perceptions of personal body weight;
- Undue influence of body weight and shape in self-evaluation; and
- Denial of the seriousness of the current low body weight.

Table 1

DSM-5 Expansion and Clarification of Feeding and Eating Disorder Criteria

Disorder	DSM-IV	DSM-5
	Required food refusal	No longer requires food refusal because it is difficult to diagnose
Anorexia Nervosa (AN)	Required amenorrhea (absence of at least three menstrual cycles)	No longer requires amenorrhea because it cannot be applied to males, premenarchal females, post-menopausal females, or females on birth control
Binge Eating Disorder (BED)	Not an official diagnosis. Although research criteria was included in Appendix B, disorder had to be diagnosed as Eating Disorder Not Otherwise Specified (EDNOS)	Included in the "Feeding and Eating Disorders" section based on studies that suggest that many individuals diagnosed with EDNOS fit into the binge eating disorder diagnostic criteria
Bulimia Nervosa (BN)	Required binge eating and compensatory behaviors twice weekly	Reduces symptom requirement to once a week
Avoidant/Restric tive Food Intake Disorder	Previously named "Feeding Disorder of Infancy or Early Childhood"	Added to "Feeding and Eating Disorders" section and expanded so it could be applied to all individuals, not just children
Other Specified Feeding or Eating Disorder	Previously considered "Eating Disorder Not Otherwise Specified" (EDNOS)	A new classification that replaces EDNOS; this disorder addresses individuals with symptoms that do not meet the full criteria for any of the other eating disorders; the clinician must specify why the presentation does not meet the full criteria
Unspecified Feeding or Eating Disorder	Previously considered "Eating Disorder Not Otherwise Specified" (EDNOS)	A new classification that replaces EDNOS; this disorder addresses individuals with symptoms that do not meet the full criteria for any of the other eating disorders; used when the clinician is unable to provide the specific reason why the clinical presentation does not meet full criteria
Pica	Located in the "Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence" section	No change to diagnosis; moved to the "Feeding and Eating Disorders" section to indicate that the diagnosis can be made for individuals of any age
Rumination Disorder	Located in the "Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence" section	No change to diagnosis; moved to the "Feeding and Eating Disorders" section to indicate that the diagnosis can be made for individuals of any age

Source: APA, 2013; Kenny, 2014.

The *DSM-5* recognizes two AN subtypes:

<u>Restricting</u> – Weight loss is accomplished by dieting, fasting, or excessive exercise with no binging or purging; and

<u>Binge-eating/purging</u> – The youth binge eats, purges, or both. Purging is defined as the use of laxatives or the act of self-induced vomiting to clear the stomach of any ingested food (APA, 2013).

Calculating body mass index (BMI) for children and adolescents is useful for determining normal weight (APA, 2013). BMI is not completely determinative because children all grow at different rates and other factors, including growth trajectories, should be taken into consideration (APA). For adults, a BMI under 17 is considered significantly underweight. However, for children, the general rule is that if the child's BMI is below the fifth percentile for their age, they are significantly underweight (APA).

## Bulimia Nervosa (BN)

BN consists of recurrent episodes of binge eating, characterized by consumption of excessive amounts of food within a discrete period of time, and lack of control in overeating during the episode. In order to prevent weight gain, the binges are followed by recurrent inappropriate responses, such as self-induced vomiting or misuse of laxatives and other medications (often referred to as purging), fasting, or excessive exercise. The binge eating and compensatory behaviors both occur, on average, at least once a week for three months or more. Finally, like other eating disorders, the individual's self-evaluation is unduly influenced by body shape and weight (APA, 2013). Recognizing BN can be challenging because many individuals with BN are within their normal weight range. Youths affected with BN are often embarrassed by their compulsion to eat and may also attempt to hide their symptoms (APA).

BN ranges in severity. The *DSM-5* outlines four levels:

- Mild: 1-3 episodes of inappropriate compensatory behaviors weekly;
- Moderate: 4-7 episodes of inappropriate compensatory behaviors weekly;
- Severe: 8-13 episodes of inappropriate compensatory behaviors weekly; and
- Extreme: 14 or more episodes of inappropriate compensatory behaviors weekly (APA, 2013).

## Binge-Eating Disorder (BED)

For the first time, the *DSM-5* has included the diagnosis of BED as an official disorder (APA, 2013). In the previous edition, BED was classified within the category Eating Disorder Not Otherwise Specified (EDNOS), with research criteria outlined in the appendices (APA, 2000). With the publication of the *DSM-5*, BED was promoted to a full-fledged diagnosis. This addition is highly significant because BED is likely to be the most prevalent eating disorder (Striegel-Moore & Franko, as cited by Kenny, Ward-Lichterman, & Abdelmonem, 2014).

BED shares the binge-eating criterion of BN of consuming an objectively large quantity of food in a relatively short time while experiencing a loss of control (Kenny, 2014). The disorder differs

from BN, however, in that individuals with BED do not engage in compensatory behaviors, such as vomiting or laxative use, after binge eating. In addition, for an individual to be diagnosed with BN, body weight and shape must unduly influence his or her self-concept. This is not necessary for a diagnosis of BED (APA, 2013).

The second criterion for BED describes behaviors, emotions, and thoughts associated with binge eating. BED includes recurrent episodes of binge eating followed by marked distress. Binge eating is accompanied by an uncontrollable feeling that one cannot stop eating. Binge eating episodes must include three or more of the following:

- Eating more rapidly than normal;
- Eating until uncomfortably full;
- Eating large amounts of food when not hungry;
- Eating alone because of embarrassment from the amount of food being consumed; or,
- Feeling disgusted with oneself, depressed, or very guilty afterwards (APA, 2013).

The binge eating occurs, on average, at least once a week for three months (APA).

### **Prevalence**

Table 2 outlines the prevalence of AN, BN, and BED.

Table 2
Prevalence by Disorder

Disorder	Prevalence Rate	s
Anorexia Nervosa	Young Females	Approximately 0.4%
	Young Males	Far less common than in young females. Diagnosis ratio: 10:1 females to males.
Bulimia Nervosa	Young Females	1% to 5%; peaking in older adolescence and young adulthood
	Young Males	Far less common than in young females. Diagnosis ratio: 10:1 females to males.
	Prevalence data is not available for young people.	
Binge-Eating Disorder	Adult Females	1.6%
	Adult Males	0.8%
	BED is more frequent in individuals seeking weight loss treatment than in the general population.	

Source: APA, 2013.

### **Causes and Risk Factors**

Attempts to identify a single cause of eating disorders have been abandoned and replaced by a more multifaceted etiological theory. Studies suggest disordered eating typically develops from a complex interaction of psychological risk factors, sociocultural influences, and biological or genetic predispositions (Striegel-Moore & Bulike, 2007; Mazzeo & Bulik, 2008; Rosen and the Committee on Adolescence, 2010).

## Psychological Risk Factors

Psychological factors include negative affect, low self-esteem, and intense dissatisfaction with appearance (Stice, 2002). In fact, body dissatisfaction is "one of the most consistent and robust risk and maintenance factors for eating pathology" (Stice). Perfectionist or impulsive traits and rigid cognitive styles have also been identified as risk factors (Herpertz-Dahlmann et al., 2001; Klump et al., 2004). In addition, factors such as dysfunctional families and relationships (e.g., conflict avoidance, significant parental enmeshment, and/or rigid/overprotective parenting) have been highly correlated with developing an eating disorder (American Psychological Association HealthCenter, 1998; Gonzalez, Kohn & Clarke, 2007).

Individuals diagnosed with eating disorders are also more likely than the general population to have a history of abuse or trauma (ADA, 2001). Specifically, sexual abuse has been reported in 20 to 50 percent of individuals with AN and BN, but BN may be more common in adolescents reporting sexual abuse during childhood. Adolescents who reported one episode of childhood sexual abuse were 2.5 times more likely to exhibit symptoms of BN than those who did not; this prevalence increased to 4.9 times more likely when two or more episodes of childhood sexual abuse were reported (Sanci et al, 2008). Females with eating disorders who have suffered from sexual abuse also demonstrate higher rates of comorbid psychiatric conditions (APA, 2000). Studies of national samples of girls and boys exposed to physical and sexual abuse have shown that, although binge and purge behaviors were nearly twice as prevalent among girls (13 percent) as boys (7 percent), boys who had experienced both physical and sexual abuse were nearly twice as likely as girls to report these behaviors to friends or family (Ackard, 2001). Inadequate coping mechanisms (e.g., poor distress tolerance and emotion regulation difficulties) are also common in those with disordered eating and may explain an individual's adoption of maladaptive eating patterns in response to trauma (Mazzeo & Bulik, 2008).

Personality traits may also affect the onset, type, and persistence of eating disorders. Traits including perfectionism, obsessive-compulsiveness, neuroticism, negative emotionality, avoiding harm, lack of self-direction, lack of cooperation, and avoidant personality disorder traits often accompany AN and BN (Cassin & von Ranson, 2005).

### Sociocultural Influences

The sociocultural model of eating disorders (Striegel-Moore & Bulik, 2007) asserts that exposure to the Western concept of the ideal body type —through magazines, television, and the Internet — promotes internalization of the thin ideal. The thin ideal is the internalized desire to have a body or body image similar to those portrayed in the mass media (Ferguson et al., 2014). Peer competition is the major driving force for body dissatisfaction. While social media may not drive body dissatisfaction, it may be used as an outlet for youth to compete (Ferguson et al.). When

individuals evaluate their own body size negatively because it is thought to vary from the ideal, body dissatisfaction may ensue. Subsequently, elevated body mass index and increased awareness of body size have been linked to the onset of excessive dieting and body dissatisfaction, both of which are prominent risk factors for eating disorders (Neumark-Sztainer et al., 2007; Stice, 2002; Striegel-Moore & Bulik).

The media has a strong influence on how individuals self-identify. They can feel either empowered or rejected due to messages relayed through mass media outlets. The power of sociocultural influences is exemplified in females as young as age nine, 40 percent of whom report a history of dieting (Maier, 2003). Objectification of the female body further reinforces the importance of achieving the thin ideal, particularly among young women (Moradi, Dirks, & Matteson, 2005). The most frequent drivers of the thin ideal are family characteristics and media such as television, movies, and advertising (Mancilla-Díaz, et al., 2012). However, the greatest influence on the thin ideal is peer pressure (Mancilla-Díaz, et al.).

Athletes, models, dancers, and performers also have a high prevalence of eating disorders (ADA, 2001). One study concluded that females participating in aesthetic sports (those that emphasize appearance, such as gymnastics) versus non-aesthetic sports or no sports experienced higher weight concerns (Davison, Ernest, Birch, as cited by Natenshon, 2016). Males who are jockeys, wrestlers, and runners have a need to be thin or to be a certain weight to compete in their respective sports. Because of this, these athletes are at increased risk of developing an eating disorder (Torres-McGehee et al., 2011). Thus, the risk of developing disordered eating symptoms increases when dietary restraint and the thin ideal assume great personal importance. This sociocultural theory may also help explain why adolescent females are more likely to develop AN and BN (Striegel-Moore & Bulik, 2007).

## Biological or Genetic Factors

Genetic factors may contribute to the development of maladaptive eating behaviors (APA, 2013; Mazzeo & Bulik, 2008; Striegel-Moore & Bulik, 2007). Specifically, first-degree female relatives and identical twin siblings of individuals with AN, BN, or BED have higher rates of eating disorder diagnoses than the general population, suggesting the existence of a biological predisposition (APA; Striegel-Moore & Bulik). Inheritance patterns, however, remain unclear. Genes can be one the largest determinants of an individual's likelihood of developing an eating disorder (Rosen and the Committee on Adolescence, 2010).

Genetic predisposition may interact with sociocultural influences to serve as a catalyst for the development of disordered eating (Mazzeo & Bulik, 2008). For example, a young woman with a family history of eating disorder patterns may seek out appearance-related feedback and/or engage in image-focused activities (e.g., swimming or cheerleading), thereby interacting in environments in which the importance of her appearance is reinforced. In this way, exposure to image-focused media may serve as an additional factor in the development of weight and shape concerns (Bulik, 2004; Mazzeo & Bulik). Molecular genetic studies found that binge eating and vomiting behaviors are highly heritable, whereas weight and concerns on self-evaluation for BN appears to be a separate environmental factor (Striegel-Moore & Bulik, 2007).

Striegel-Moore and Bulik (2007) further propose that various neonatal complications may lead to an increased risk for AN. Longitudinal studies have shown that poor maternal feeding behaviors, such as food restriction and weight control behaviors, may lead to premature births and be an indicator of the future onset of AN. Finally, some researchers have found that abnormal serotonin metabolism may play a greater role in individuals with BN than those with AN, suggesting biological differences in individuals with these two diagnoses (Murphy, Cowan & Sederer, 2001).

## Comorbidity

Comorbidities for eating disorders can be medical and/or psychiatric in nature. Both issues are discussed in the paragraphs which follow.

### Medical

While feeding and eating disorders are considered to be psychiatric in nature, accompanying nutrition and medical problems may make them life-threatening (ADA, 2001). As noted by the National Institute of Mental Health (NIMH), of particular concern is the increased mortality rate of individuals with eating disorders, particularly those diagnosed with AN (2001). Recent studies suggest that individuals diagnosed with AN are more likely to suffer premature death (Steinhausen, 2008). The mortality rate attributed to AN in females aged 15 to 24 is approximately 12 times higher than the annual death rate for all causes. According to NIMH, the most common cause of death in those with AN are complications of the disorder, such as starvation, cardiac arrest, electrolyte imbalance, and even suicide. Mortality rates for BN are lower than AN, but remain a serious danger (Fichter & Quadflieg, 2004).

Adolescents with eating disorders face the risk of potentially irreversible medical complications, including:

- Growth retardation when the eating disorder occurs prior to closure of the epiphyses;
- Pubertal delay or arrest;
- Impaired acquisition of peak bone mass during adolescence;
- Increased risk of osteoporosis in adulthood; and
- Lost brain tissue and increased cerebrospinal fluid (ADA, 2001; Scudder, 2011).

Malnutrition and excessive exercise may also contribute to loss of bone mass in those suffering from AN and BN (Herpertz-Dahlmann, 2008). The effects on bone density may be permanent, and increase the risk of fractures through adolescence and throughout life (Scudder, 2011). The changes in the brain caused by eating disorders will alter mood and cognitive ability, both of which resolve upon weight recovery (Scudder). However, there is question about the long-term effects on brain mass; most brain mass returns after weight restoration, but some deficits do remain (Scudder).

In chronic eating-disordered behaviors, additional physical comorbidities are common. For example, some individuals with eating disorders experience amenorrhea, constipation, abdominal pain, cold intolerance, lethargy, emaciation, permanent dental damage, and/or cardiovascular problems, typically the result of semi-starvation and/or purging (APA, 2013). Symptoms

associated with dehydration, such as the imbalance of electrolytes, require immediate medical attention, including hospitalization, when it is necessary to address the side effects of dehydration and/or to restore weight (APA).

## **Psychiatric**

It is common for individuals suffering from eating disorders to experience additional significant distress due to comorbid psychological conditions. Disorders comorbid to BED are comparable to those comorbid to AN and BN; the severity of the comorbid disorder is linked to the severity of binge eating, not to the degree of obesity (APA, 2013). Psychological disorders such as bipolar, depressive, and anxiety disorders often co-occur with AN, BN, or BED (APA, 2013). As high as 50 percent of individuals with a feeding and eating disorder also have depression (National Association of Anorexia Nervosa and Associated Disorders [ANAD], n.d.).

Mood disorders frequently occur at the same time BN presents, and many individuals attribute mood disturbances to BN (APA, 2013). The mood disorders often end after effective BN treatment (APA). Substance abuse disorders may be present in as high as 30 percent of those with BN and 12 to 18 percent of those with AN, the latter of which may be employed to suppress appetite (APA, ADA, 2001). Alcohol and substance use disorders are more likely to be found with the binge eating/purging subtype of AN (APA). Research by Herpetz-Dahlmann (2008) suggests that female youth diagnosed with attention-deficit/hyperactivity disorder (ADHD) may also be more likely to develop maladaptive eating patterns and distorted body image. Researchers have yet to determine the order of onset of psychological comorbidities. It is unclear whether conditions develop because of the isolation, stigma, and physiological changes brought on by eating disorders or whether they existed prior to the development of unhealthy eating habits (American Psychological Association HealthCenter, 1998).

Many individuals with AN may be diagnosed with an anxiety disorder or related symptoms prior to the eating disorder onset (APA, 2013). Anxiety may also accompany BN, including fear in social situations, but, as with mood disorders, anxiety frequently remits after effective BN treatment (APA). Additionally, obsessive-compulsive disorder (OCD) may accompany AN, especially the restricting type (APA). Furthermore, in the majority of participants the onset of anxiety disorders preceded symptoms of eating disorders (Swinbourne et al., 2012). Further research is needed, but there seems to be a strong correlation between the two disorders.

The risk of suicide in individuals diagnosed with an eating disorder is substantial. Individuals with an eating disorder are significantly more likely to attempt suicide than those not diagnosed with an eating disorder (Pompili et al., 2006). One study of adult females with eating disorders suggests that those with recurring suicidal thoughts usually developed their disorders at younger ages (Ham, 2004). Individuals with BN report a greater number of suicidal attempts (25 to 35 percent), compared to those with AN (10 to 20 percent) (Herpertz-Dahlmann, 2008). Researchers speculate that the link between purging and suicidal attempts may point to a general lack of impulse control, whereas the higher prevalence of suicidal thoughts among individuals with AN suggests chronic self-harming behavior (Ham).

### Assessment

The earlier an eating disorder is diagnosed and subsequently treated, the more likely a full recovery will be made (Rosen and the Committee on Adolescence, 2010; Scudder, 2011). The American Academy of Pediatrics recommends that pediatricians also ask pre-adolescents and adolescents about eating patterns and body image (Rosen and the Committee on Adolescence). When weight is regularly tracked, pediatricians can look for a change in weight to determine whether a youth is losing, gaining, or maintaining weight in a healthy manner (Rosen and the Committee on Adolescence; Scudder). Comprehensive symptom assessment requires the utilization of multiple cognitive and behavioral measures, as well as a thorough medical examination. This physical examination typically includes assessments of heart rate, blood pressure, body temperature, blood count, biochemical profile (e.g., electrolytes), electrocardiogram (ECG), electroencephalogram (EEG), magnetic resonance imaging (MRI), and computed tomography (CT) (Herpertz-Dahlmann, 2008).

For AN and BN, often the first physical signs of an eating disorder are changes in the mouth, including enlarged salivary glands, changed tooth color, tissue loss or lesions, heightened sensitivity to temperature, and tooth decay from induced vomiting (NEDA, 2002). Dental practitioners are typically the first to identify signs of BN. According to the NEDA, tooth erosion is evident in approximately 89 percent of individuals with BN. Other frequent indicators of BN are an enlarged parotid/salivary gland, scars on the back of the hand from induced vomiting, and dehydration.

For AN, youth may present the following physical symptoms: dry skin that, when pinched and released, stays pinched; dehydration; abdominal pain; constipation; lethargy; dizziness; fatigue; infrequent or absent menstrual periods in females who have reached puberty; intolerance to cold temperatures; emaciation; development of lanugo (fine, downy body hair); and yellowing of the skin (University of Virginia Health System, 2009; NIMH, 2001).

Typically, clinicians use self-report questionnaires and structured/semi-structured clinical interviews to assess cognitive and behavioral eating disorder symptoms, as well as other psychiatric comorbidities. Valid and reliable interview tools are included in Table 3.

For assessment purposes, it is important to understand that individuals with disordered eating symptoms tend to self-evaluate their symptoms as compatible with their attitudes, behaviors, and beliefs (Keel & Haedt, 2008). Therefore, self-report outcomes may be biased and should be considered in conjunction with findings from a physical examination. Family history of disordered eating behaviors and attitudes should also be explored in order to gain a comprehensive understanding of the individual's predisposition to disordered eating behaviors and cognitions (Mazzeo & Bulik, 2008). Assessing parental feeding patterns is also important, as caregivers will likely be integral components of the treatment program and may themselves encounter difficulties initiating and maintaining a healthy relationship with food and weight.

Table 3
Suggested Assessment Tools

Name of Measure	Measure Type	Who Completes	Generated Information
Interview for the Diagnosis of Eating Disorders (4th Edition) (IDED-IV)	Valid & and BED we symptom seven interview tools  Clinician including concerning eating, weight shape, and discontinuous concerning to the content of the co	QI	Diagnoses of AN, BN, and BED with symptom severity,
Eating Disorder Examination (12th Edition) (EDE)		eating, weight and shape, and dietary restraint	
Eating Disorder Diagnostic Scale (EDDS)			
Binge Eating Scale (BES)			
Eating Disorder Examination Questionnaire (EDED-Q)			
Eating Attitudes Test (EAT)	Empirically		
Eating Disorder Inventory-Revised (EDI-3)	supported, self-rating	Youth	Symptom ratings
Bulimia Test-Revised (BULIT-R)	scales		
Multiaxial Assessment of Eating Disorder Symptoms (MAEDS)			
Stirling Eating Disorder Scale (SEDS)			
Eating Inventory (EI)			

Sources: Commission on Youth Graphic of references listed in text.

The Eating Disorder Examination (EDE), once regarded as the "gold standard" for determining BN symptomology, is now considered to be more effective at determining body dissatisfaction (Sandberg & Erford, 2013). Without questioning additional informants, such as parents, adolescents are more likely to downplay aspects of their eating disorder and score lower on the EDE (House, et al., 2008). These adolescents deny their symptoms and do not desire help (Mariano et al., 2013). However, when clinicians pair the EDE with recent modifications by Couturier, et al., the results more accurately diagnose AN in adolescents (House, et al.). The Development and Well-Being Assessment (DAWBA) may be a more effective assessment tool, and clinicians should consider both when diagnosing potential eating disorders (House, et al.; Moya et al., 2005).

The *DSM-5* suggests using body mass index (BMI) as a preliminary indicator of AN or BN. Table 4 outlines the new guidelines to be used when BMI is taken into consideration.

Table 4

BMI Severity Ranges
for Underweight Individuals

Severity	ВМІ
Mild	$\geq 17 \text{ kg/m}^2$
Moderate	$16 - 16.99 \text{ kg/m}^2$
Severe	$15 - 15.99 \text{ kg/m}^2$
Extreme	$< 15 \text{ kg/m}^2$

Source: APA, 2013.

### **Treatment**

The earlier an eating disorder is identified and treated, the better the chances for recovery (Levine & Maine, 2005; Steinhausen, 2008; Scudder, 2011). However, individuals with eating disorders are among the least likely to seek treatment (American Psychological Association HealthCenter, 1998). Pediatricians are crucial not only in identifying eating disorders, but also in managing the treatment process, including coordinated care with nutrition and mental health professionals (Rosen and the Committee on Adolescence, 2010; Scudder). A comprehensive treatment plan should include medical care and monitoring, psychosocial interventions, nutritional counseling and, when appropriate, medication management (NIMH, 2001). Treatment providers should also discuss with both the individual and his/her family the role genetics may play in these disorders (Mazzeo & Bulik, 2008); this can minimize the guilt family members may experience and increase their willingness to be active participants in the treatment process.

Treatment locations range from intensive patient settings, in which general medical consultation is readily available, to partial hospital and residential programs with varying levels of outpatient care. The individual's weight, cardiac, and metabolic status are the most important physical parameters for determining treatment setting. Individuals who weigh under 85 percent of their estimated healthy weights are likely to require a highly structured program and possibly 24-hour hospitalization. Hospitalization should occur before the onset of medical instability, as manifested by severely abnormal vital signs. Specifically, once the youth begins to display a rapid decline in food intake and dramatic loss of weight, treatment providers should seriously consider hospitalization. Furthermore, the presence of external stressors or comorbid psychiatric disorders may have a significant impact on this decision.

Many individuals have a limited response to treatment and require long-term monitoring and intervention (U.S. Department of Health and Human Services, 1999). Because AN, in particular, is chronic in nature, those diagnosed with AN may struggle with the disorder for five to ten years or longer (Medscape Internal Medicine, 2006). Individuals with AN may be particularly difficult to treat because they are highly resistant to weight gain and are likely to exhibit a fear of losing control (Murphy, Cowan, & Sederer, 2001). Thus, ethical considerations may arise during the course of treatment, and involuntary hospitalization may be the necessary course. The prognosis in adolescents with eating disorders is much better than that in adults (Rosen and the Committee

on Adolescence, 2010). Even with a higher probability of success, families should be aware that it might take as long as 10 years from the commencement of treatment to behavioral cure, including normal eating and normal weight (Rosen and the Committee on Adolescence).

The majority of studies have been conducted with adolescents over age 15, although evaluation of adolescent males is limited (Keel & Haedt, 2008). The limitations of research of eating disorder interventions for males and young children should be acknowledged when considering the course of treatment.

Unless otherwise cited, information in the rest of this section is taken from APA (2000).

# Anorexia Nervosa (AN)

According to the APA (2000), the treatment methods described in the paragraphs that follow and in Table 5 are the most empirically supported for individuals with AN. The treatment of AN generally occurs in three primary phases:

- Restoring the weight lost by severe dieting and purging;
- Treating psychological disturbances, such as distorted self-perception, low self-esteem, and interpersonal issues; and
- Achieving long-term, full recovery (NIMH, 2001).

### What Works – Evidence-based Treatments

Nutritional rehabilitation – Evidence suggests that nutritional monitoring is effective in helping individuals return to a healthy weight, so long as it is conducted in a setting that meets the individual's needs. Increasing calories consumed may be difficult, but smaller, frequent meals, calorie dense foods, and substituting fruit juice for water may help negate psychological barriers, such as aversion to a feeling of fullness (Rosen and the Committee on Adolescence, 2010). For severely underweight individuals, individual treatment has been found to be most effective. Clinicians have reported that, as weight is restored, other eating disorder and psychiatric comorbid symptoms diminish; however, they often do not disappear completely. Psychoeducational nutrition groups have also been associated with positive outcomes (Herpertz-Dahlmann & Salbach-Andrae, 2008). Although helpful, it is important that nutrition counseling serve as only one component of a multidisciplinary treatment approach.

<u>Family-based psychotherapy</u> – Family-based psychotherapy is considered the gold standard of treatment for AN in adolescents (Bailey et al., 2014; Murray, Thornton, & Wallis, 2012). The goal of family therapy is to involve family members in symptom reduction and to deal with family relational problems that may contribute to AN. Some studies have found that family therapy is associated with greater long-term benefits and better retention rates compared to individual psychotherapy (Bulik et al., 2007; Keel & Haedt, 2008; Lock et al., 2010). This seems to be especially true when the family is treated as part of the treatment team. However, these findings are limited to generalizations because the individuals in these studies often did not receive both family and individual treatment, which commonly occurs in practice. Family-based therapy occurs over the following three stages:

- 1. Parents, along with the therapist, take responsibility to ensure the adolescent is eating sufficiently and controlling other pathologic weight control methods. Substantial weight recovery occurs before moving to the second phase.
- 2. Parents and the therapist help the adolescent gradually take over responsibility for his or her eating. Weight is restored in the second phase, and then the family moves onto the third phase.
- 3. The family addresses more general issues of the adolescent's development and how they were disrupted by the eating disorder (Rosen and the Committee on Adolescence, 2010).

Family psychotherapy may not be appropriate for families in which one or both parents exhibit psychopathy or hostility to the affected child, and it may not be appropriate for the most medically compromised adolescents (Rosen and the Committee on Adolescence, 2010).

<u>In-Patient behavioral programs</u> – These programs commonly provide a combination of nonpunitive reinforcers, such as privileges linked to weight goals and desired behaviors. They have been shown to produce good short-term therapeutic effects. Adolescents with AN may have the best outcomes after structured in-patient or partial hospitalization treatment. For example, one study found that adolescents who had received systematic in-patient treatment with close cooperation among parents and the pediatric and child and adolescent psychiatry departments had good outcomes even three to 14 years after treatment (APA, 2000).

### What Seems to Work

<u>Cognitive Behavioral Therapy (CBT)</u> – When specifically directed at the eating disorder symptoms and underlying conditions, CBT appears quite promising. However, the long-term effects are not yet well known (Butler, et al., 2005 citing Wilson & Fairburn, 1998). Results from the treatment of adolescent depression and anxiety disorders suggest that age appropriate modifications to adult CBT treatment programs for eating disorders may well be effective (Gowers, 2006).

<u>Pharmacological treatments</u> – No medication is currently approved by the Food and Drug Administration (FDA) to treat AN (Powers & Bruty, 2008). The most typical medications prescribed are antidepressants; however, they should not be used in the acute phase of treatment for severely malnourished individuals as they are more sensitive to their side effects. Psychological symptoms, particularly those related to mood disorders, seem to be exacerbated during periods of semi-starvation and significant weight loss (Keys, 1950). Thus, before prescribing psychopharmaceuticals to relieve symptoms associated with these individuals' comorbidities, clinicians should first work towards minimizing the occurrence of purging behaviors and begin the refeeding process (Herpertz-Dahlmann, 2008).

Selective serotonin reuptake inhibitors (SSRIs) are frequently used for individuals whose depressive, obsessive, or compulsive symptoms persist in spite of or in the absence of weight gain. However, studies have not shown SSRIs to be effective for purposes of restoring weight or preventing relapse (Kuo, 2006). The use of SSRIs for adult AN has not produced enough encouraging results, with safety concerns and lack of outcome data that makes application to younger populations problematic (Bailey et al., 2014).

Preliminary evidence suggests that some atypical antipsychotics (e.g., olanzapine) may minimize some AN symptoms, especially in those diagnosed with the binge-purge subtype (Powers & Bruty, 2008). However, the benefits must be weighed while accounting for side effects, such as metabolic disorders and weight gain, which may prompt poor treatment adherence in resistant clients.

## **Not Adequately Tested**

<u>Individual psychotherapy</u> – The efficacy of this form of treatment remains uncertain. No controlled studies have reported whether specific psychotherapeutic interventions are effective for nutritional recovery. Clinicians generally agree that psychotherapy is almost always beneficial during acute refeeding; however, in starving individuals, who are often negative, obsessive, or mildly cognitively impaired, this form of treatment may often be ineffective. Psychotherapy may be a useful method in treating co-occurring disorders. Keel and Haedt (2008) present a review of various individual treatment programs that, based on preliminary analyses, may prove to be efficacious in the future (e.g., self-psychology, CBT, virtual reality).

### **What Does Not Work**

<u>Group psychotherapy</u> – Practitioners have found that group psychotherapy programs conducted during an acute phase among individuals with AN may be ineffective and can have negative therapeutic effects, as individuals in the group may compete to be the thinnest or exchange counter-therapeutic techniques on simulating weight gain or hiding food.

<u>12-step programs</u> – No data regarding the short- or long-term effectiveness of this form of treatment is available. However, use of addiction-based programs in isolation is discouraged, as individuals will deprive themselves of the benefits of conventional treatments and may also be exposed to misinformation by well-meaning individuals in these groups.

<u>Somatic treatments</u> – Vitamin and hormone treatments, electroconvulsive therapy, and other somatic treatments have been tried in uncontrolled studies. Both calcium/vitamin D supplements and hormone replacement therapy have been effective in improving bone mass (Golden, 2003). However, hormone injections also initiate the return of females' menses, thereby falsely representing their return to biological health. Still, none have been shown to have any significant therapeutic value to individuals with AN.

<u>Contraindicated Medications</u> – The use of tricyclic antidepressants (TCA) for adult AN has not produced enough encouraging results, with safety concerns and lack of outcome data that makes application to younger populations problematic (Bailey et al., 2014). Tricyclic antidepressants should be avoided in underweight individuals and in individuals who are at risk for suicide (APA, 2000).

Table 5
Summary of Treatments for Anorexia Nervosa

What Works	
Nutritional rehabilitation	Entails developing meal plans and monitoring intake of adequate nutrition to promote healthy weight gain.
Family psychotherapy	Family members are included in the process to assist in reduction of symptoms and modify maladaptive interpersonal patterns.
In-patient behavioral programs	Individuals are rewarded for engaging in healthy eating and weight-related behaviors.
What Seems to Work	
Cognitive behavioral therapy (CBT)	Needs further study to be well established; it is used to change underlying eating disorder cognitions and behaviors.
Pharmacological treatments	Used primarily after weight restoration to minimize symptoms associated with psychiatric comorbidities.
Not Adequately Tested	
Individual psychotherapy	Controlled trials have not supported this treatment; however, it may be beneficial during the refeeding process and to minimize comorbid symptoms.
What Does Not Work	
Group psychotherapy	May stimulate the transmission of unhealthy techniques among group members, particularly during acute phase of disorder.
12-step programs	Not yet tested for their efficacy; discouraged as a sole treatment.
Tricyclic antidepressants	Tricyclic antidepressants are contraindicated and should be avoided in underweight individuals and in individuals who are at risk for suicide
Somatic treatments	To date, treatments such as vitamin and hormone treatments and electroconvulsive therapy show no therapeutic value.

Sources: Commission on Youth Graphic of references listed in text.

## Bulimia Nervosa (BN)

The primary goal of treatment with individuals with BN is to reduce or eliminate binge eating and purging behavior. According to NIMH (2001), nutritional rehabilitation, psychosocial intervention, and medication management strategies are therefore often used. Specifically, treatment includes establishing regular, non-binge meals, improving attitudes related to the disorder, encouraging healthy but not excessive exercise, and resolving any co-occurring mental health disorders such as anxiety or mood disorders. The treatments most commonly utilized in individuals with BN are listed in Table 6 and described in the paragraphs that follow.

### What Works – Evidence-based Treatments

<u>Cognitive behavioral therapy</u> (CBT) – This form of psychotherapy, when specifically directed at BN symptoms and underlying conditions, is the intervention for which there is the most evidence of efficacy. It has been found to lead to significant reductions in binge eating, vomiting, and laxative abuse (Keel & Haedt, 2008). Some consider CBT the "gold standard" of therapy. It involves a combination of psychoeducation, self-monitoring, adjusting reactions to cues, confronting and restructuring automatic thoughts, problem solving, exposure while preventing response, and preventing relapse (Bulik et al., 2012).

<u>Combined treatments</u> – There is generally a better response to CBT than pharmacotherapy; however, the combination of these two methods has been found to be superior to either alone (APA, 2000).

#### What Seems to Work

<u>Pharmacological treatments</u> – Individuals with BN are typically more responsive to pharmacologic interventions than individuals with AN (Berkman et al., 2006). For adult BN, SSRIs have produced positive findings with moderate effects on binge/purge frequency and reviews indicate their potential utility with young people (Bailey et al., 2014). However, this needs to be balanced with the lack safety data in this younger population, particularly given the controversy surrounding the use of SSRIs with adolescents and young adults in the depression field (Bailey et al.). CBT, however, appears to be superior to antidepressants; therefore, current recommendations support the use of medications for youth who refuse CBT or who do not have an optimal response to CBT (Lock, La Via & the American Academy of Child and Adolescent Psychiatry [AACAP] Committee on Quality Issues [CQI], 2014).

The SSRI fluoxetine is the only medication approved by the FDA for the treatment of BN in adults (Powers & Bruty, 2008; NIMH, 2011). Pharmacological treatments have been found to be especially effective for individuals with symptoms of depression or anxiety and for those who have not responded well to psychotherapy alone (NIMH, 2001; NIMH, 2011).

### **Not Adequately Tested**

<u>Individual psychotherapy</u> – While there is support for some individual therapies aside from CBT in case studies and reports, the efficacy of these methods has not been supported by controlled trials. When compared to CBT, most short-term trials have been found it to be less effective (Keel & Haedt, 2008, Lock, 2010).

<u>Family therapy</u> – Recently, literature suggests that family therapy may be more beneficial (i.e., lower rates of remission) than individual supportive psychotherapy for young adolescents with a BN diagnosis (Keel & Haedt, 2008; Lock, 2010). However, outcomes should be considered preliminary at this time.

Table 6
Summary of Treatments for Bulimia Nervosa

What Works	
Cognitive behavioral therapy (CBT)	The most effective independent treatment option; it is used to change underlying eating disorder cognitions and behaviors.
Combined treatments	A combination of CBT and pharmacotherapy seems to maximize outcomes.
What Seems to Work	
Pharmacological treatments	Antidepressants, namely SSRIs, have effectively reduced binge/purging behaviors, as well as comorbid psychiatric symptoms.
Not Adequately Tested	
Individual psychotherapy	Compared to CBT, few individual therapeutic approaches have been effective in reducing symptoms.
Family therapy	May be more beneficial than individual psychotherapy, but outcomes should be considered preliminary at this time.
What Does Not Work	
Bupropion	Bupropion has been associated with seizures in purging individuals with BN and is contraindicated
Monoamine oxidase inhibitors (MAOIs)	MAOIs are potentially dangerous in individuals with chaotic binging and purging and their use is contraindicated.
12-step programs	Discouraged as a sole treatment because they do not address nutritional or behavioral concerns.

Sources: Commission on Youth Graphic of references listed in text.

## **What Does Not Work**

<u>12-step programs</u> – Addiction-based programs are not recommended as the sole treatment approach for individuals with BN, as they do not attend to nutritional considerations or behavioral deficits (APA, 2000).

### **Contraindicated Medications**

The following medications should not be used to treat individuals with BN:

Bupropion has been associated with seizures in purging individuals with BN and should not be used in this population (APA, 2000).

Monoamine oxidase inhibitors (MAOIs) are also potentially dangerous in individuals with chaotic binging and purging; therefore, their use should be limited (APA, 2000).

# Binge Eating Disorder (BED)

The treatment goals and strategies for BED are similar to those for BN. The primary difference in the two disorders is that individuals with BED may present with difficulties associated with being overweight rather than being malnourished. Consequently, the treatment strategies tend to diverge only in the nature of medical interventions. However, BED has been relatively unexamined in younger patients and no treatments yet meet evidence-based criteria.

#### What Seems to Work

<u>Cognitive Behavioral Therapy (CBT)</u> – Research in adults supports the effectiveness of CBT for treatment of BED, and CBT is the most studied and well-established psychological treatment for BED (Iacovino et al., 2012).

CBT, both individual and group setting, has been shown to be effective in reducing binge eating (Berkman, et al., 2006). Effective treatments that disrupt the binge-eating cycle and establish a structured pattern of eating allow the individual to experience less hunger, deprivation, and negative feelings about food and eating. Additionally, hunger and negative feelings, which most likely prompt binge eating, must also be reduced, decreasing the frequency of binges (NIMH, 2001).

Interpersonal Psychotherapy (IPT) – Preliminary studies support the use of interpersonal psychotherapy (IPT) to treat BED (Lock, La Via & the American Academy of Child and Adolescent Psychiatry [AACAP] Committee on Quality Issues [CQI], 2014). The interpersonal model of binge eating asserts that social problems create an environment in which binge eating develops as a coping mechanism, serving to reduce negative affect in response to unfulfilling social interactions (Iacovino et al., 2012). Binge eating may actually worsen interpersonal problems by increasing social isolation and weakening relationships, thereby maintaining the eating disorder. People with BED may binge to cope instead of expressing this negative affect. IPT helps youth acknowledge and express this so that they can better manage negative feelings without turning to food (Iacovino et al.). IPT also seeks to reduce binge eating pathology by supporting the development of healthy interpersonal skills that can replace maladaptive behaviors and promote a positive self-image.

# **Not Adequately Tested**

Mindfulness techniques and dialectical behavior therapy (DBT) have also been suggested as future areas of treatment research for BED (Mazzeo & Bulik, 2008). Furthermore, compared to youth in the control group, youth who participated in a yoga-based intervention employing mindfulness and dissonance-based exercises experienced reductions in body dissatisfaction and uncontrolled eating (Scime & Cook-Cottone, 2008). The newly created diagnostic classification will allow for additional study of CBT from a clinical research perspective.

Table 7
Summary of Treatments for Binge Eating Disorder

What Works				
There are no evidence-based practices at this time				
What Seems to Work				
Cognitive behavioral therapy (CBT)	The most effective independent treatment option; it is used to change underlying eating disorder cognitions and behaviors			
Interpersonal psychotherapy (IPT)	Attempts to reduce the use of binge eating as a coping mechanism by supporting the development of healthy interpersonal skills			
Pharmacological treatments	Antidepressants, namely SSRIs, have effectively reduced binge/purging behaviors, as well as comorbid psychiatric symptoms			
Not Adequately Tested				
Dialectical behavior therapy (DBT)	Those treatments are suggested as future areas of research			
Mindfulness and yoga- based interventions	These treatments are suggested as future areas of research			
What Does Not Work				
Pharmacological treatments	Although may reduce binge eating in high doses, does not necessarily help with weight loss; in addition, very high placebo response rate and relapse rate			
Nutritional rehabilitation and counseling	Although initial weight loss is associated with these treatments, weight is commonly regained			
12-step programs	Discouraged as a sole treatment because they do not address nutritional or behavioral concerns			

Sources: Commission on Youth Graphic of references listed in text.

#### **What Does Not Work**

<u>Nutritional rehabilitation and counseling</u> – Restrictive diets used with group behavioral weight control programs have been associated with substantial initial weight loss, but are often less effective during or following the refeeding stage. Weight is commonly regained during this period.

<u>12-Step Programs</u> – Discouraged as a sole treatment because many do not address nutritional or behavioral concerns.

<u>Pharmacological treatments</u> – Antidepressants may be used to treat BED and related syndromes. Patients may reduce binge eating, but not necessarily lose weight, while taking high doses of antidepressants (Yager, 2009). However, there is a very high placebo response rate (around 70 percent), and individuals tend to relapse after medication is discontinued.

#### **Cultural Considerations**

Individuals with eating disorders represent a wide range of demographics (ADA, 2001). Disorders appear to be more prevalent among Native Americans and in Latinos and Caucasians and less common among Asians and African Americans (APA, 2000). Researchers have also found that African American females are more likely to develop BN than AN and are more likely to purge with laxatives than by vomiting (APA). Moreover, African American male youth engage in BED behaviors more frequently than female Caucasian youth (Johnson, Rohan, & Kirk, 2002). However, methods for assessing disordered eating symptoms in culturally diverse populations are limited (Bardone-Cone & Boyd, 2007), as are evidence-based treatment options (Keel & Haedt, 2008).

The *DSM-5* warns clinicians to consider that certain cultural groups do not utilize mental health services for eating disorders frequently, including Latinos, African Americans, and Asian Americans (APA, 2013). Additionally, clinicians should be aware of different presentations across cultures. Asian populations may be more "fat phobic," but may also complain of gastrointestinal discomfort rather than an eating disorder (APA). Because values concerning weight and shape vary among cultures, clinicians must be mindful of varying standards of beauty, acceptance, and what it means to be "perfect" in the modern world (APA, 2000). It is also important to note that AN is detectable in all socioeconomic classes. Thus, higher socioeconomic status does not appear to be a major factor in the incidence of these disorders, as once was surmised (ADA, 2001).

Males with an eating disorder often go undiagnosed due to their embarrassment about not living up to the image of the ideal male body. In particular, males who binge or overeat compulsively may go undiagnosed, given society's unwillingness to accept such behavior in a male (Knowlton, 1995). Relatively little is known about males with eating disorders; thus, clinicians should be careful not to avoid overlooking eating disorder symptoms in males.

#### **Overview for Families**

Table 8 summarizes the primary features of eating disorders for families. Table 9 summarizes signs and symptoms of eating disorders.

Table 8

Summary of Primary Features of Eating Disorders for Families

Disorder	Description of Primary Features	
Anorexia Nervosa	Distorted body image  Causes children and adolescents to severely restrict their food intake May lead to: Significant weight loss, and Dangerous side-effects including malnutrition and dehydration	
Bulimia Nervosa	Excessive eating followed by purging methods like: <ul> <li>Laxatives,</li> <li>Enemas,</li> <li>Diuretics,</li> <li>Vomiting, and/or</li> <li>Exercising</li> </ul>	
Binge Eating Disorder	Frequent episodes of out-of-control eating  • The youth cannot control his or her eating  • The youth eats significantly more than most people would in the same time  No purging like in bulimia nervosa  New diagnosis in <i>DSM-5</i>	

Source: APA, 2013.

Table 9
Summary of Signs and Symptoms of Eating Disorders for Families

Disorder	Signs and Symptoms		
Anorexia Nervosa	<ul> <li>Perfectionist traits;</li> <li>Often a high achiever;</li> <li>Low self-esteem, irrationally believing he or she is fat regardless of how thin he or she becomes;</li> <li>Desperate need for a feeling of mastery over his or her life; and</li> <li>Starving oneself, sometimes to the point of seriously damaging one's body, which can lead to death.</li> </ul>		
Bulimia Nervosa	<ul> <li>Binging on huge quantities of high-caloric food; and/or</li> <li>Purging calories by self-induced vomiting and often by using laxatives.</li> <li>The child or adolescent may alternate binges and severe diets and, as a result, have severe weight fluctuations.</li> <li>Teens may run water while spending long periods of time in the bathroom to hide the signs of vomiting.</li> <li>Purging may seriously damage health, causing dehydration and hormonal imbalance, depleting important minerals, and damaging vital organs.</li> </ul>		
Binge Eating Disorder	<ul> <li>The child or adolescent eats copious amounts of food, but does not purge.</li> <li>Binge eating can lead to future purging.</li> </ul>		

Source: Rosen and the Committee on Adolescence, 2010.

# **Resources and Organizations**

#### **Academy for Eating Disorders (AED)**

https://www.aedweb.org/home

# Eating Disorders Coalition for Research, Policy & Action (EDC)

http://www.eatingdisorderscoalition.org/

#### **Eating Disorders Treatment**

http://www.eating-disorder.com/

# **EDReferral.com** (Eating Disorder Referral and Information Center)

https://www.edreferral.com/

# Johns Hopkins Eating and Weight Disorders Program

https://www.hopkinsmedicine.org/psychiatry/specialty\_areas/eating\_disorders/index.html

#### **Maudsley Parents**

http://www.maudsleyparents.org/

# National Association of Anorexia Nervosa and Associated Eating Disorders

http://www.anad.org/

#### **National Eating Disorders Association (NEDA)**

Information & Referral Helpline: 800-931-2237

https://www.nationaleatingdisorders.org/

#### **National Institute of Mental Health (NIMH)**

https://www.nimh.nih.gov/index.shtml

# **Society for Adolescent Health and Medicine (SAHM)**

https://www.adolescenthealth.org/Home.aspx

#### **Substance Abuse and Mental Health Services Administration (SAMHSA)**

National Mental Health Information Center

https://www.samhsa.gov/

# Virginia Resources and Organizations

#### **James Madison University**

Help Overcome Problems with Eating and Exercise (HOPE)

https://www.jmu.edu/healthcenter/PreventionandEducation/hope-multiregion.shtml

### University of Virginia

Elson Student Health Center

http://www.virginia.edu/studenthealth/

# Virginia Commonwealth University Health System

Department of Psychiatry

https://psych.vcu.edu/

Virginia Treatment Center for Children (VTCC)

http://www.chrichmond.org/Services/Outpatient-Programs.htm

#### **Virginia Polytechnic Institute and State University (VA Tech)**

**Cook Counseling Center** 

http://ucc.vt.edu/self\_help\_support\_stategies/help\_eating\_disorders.html

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# DISRUPTIVE, IMPULSE-CONTROL, AND CONDUCT DISORDERS

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#### Introduction

All children and adolescents exhibit challenging or disruptive behavior at times due to stress or events that are taking place in their homes, schools, or communities. However, disruptive, impulse-control, and conduct disorders are more severe problems that last for a longer period than normal "acting out" behaviors (American Psychiatric Association [APA], 2015). This category of disorders involves problems concerning the self-control of emotions and behaviors (APA, 2013). These disorders are unique in that their associated behaviors are frequently in conflict with societal norms/authority figures and even violate the rights of others (e.g., aggression, destruction of property) (APA). The underlying causes of the problems in the self-control of emotions and behaviors can vary greatly among youth diagnosed with these disorders. Disruptive, impulse-control, and conduct disorders are associated with patterns of escalating problem behaviors leading to negative life consequences, including social, academic, and occupational functioning, substance abuse and, potentially, incarceration (American Academy of Child & Adolescent Psychiatry [AACAP], 2007).

# Recent Changes from the DSM-IV to the DSM-5

In 2013, the American Psychiatric Association (APA) released the fifth edition of the *Diagnostic* and Statistical Manual of Mental Disorders (DSM-5) to replace the fourth text revision (DSM-IV-TR). The DSM-5 chapter on disruptive, impulse-control, and conduct disorders is new to DSM-5. It combines oppositional defiant disorder (ODD), conduct disorder (CD), and disruptive behavior disorder not otherwise specified (DBDNOS) with disorders in the "Impulse-Control Disorders Not Otherwise Specified" chapter (intermittent explosive disorder [IED], pyromania, and kleptomania). Previously, ODD, CD, and DBDNOS were included in the chapter "Disorders

Usually First Diagnosed in Infancy, Childhood, or Adolescence." (Gathright & Tyler, 2014). Attention-deficit/hyperactivity disorder (ADHD) was previously included in the *DSM-IV-TR* as a disruptive behavior disorder, but it is now listed in *DSM-5* with the neurodevelopmental disorders. Figure 1 outlines the changes made to ODD and CD, the two most commonly occurring disruptive, impulse-control, and conduct disorders in youth.

#### Figure 1

# Oppositional Defiant Disorder and Conduct Disorder Changes from the *DSM-IV-TR* to the *DSM-5*

#### **Oppositional Defiant Disorder**

- The symptoms of ODD are now grouped into three types to highlight both emotional and behavioral symptoms.
- The *DSM-5* allows for a co-occurring diagnosis of ODD and CD.
- A new guidance note on the frequency typically required to be considered symptomatic distinguishes the symptoms of ODD from those which commonly occur in normally developing children.
  - Children younger than five years old must exhibit this behavior most days, while children over five must exhibit at least once weekly.
  - These symptoms should be present over a six month timeframe.
- Finally, the *DSM-5* establishes a severity rating because it has been shown that the pervasiveness of symptoms across settings is an important indicator of severity of the individuals ODD.

# **Conduct Disorder**

- The *DSM-5* did not change CD other than to add a specifier which distinguishes those with a callous and unemotional interpersonal style across multiple settings and relationships.
- The "with limited prosocial emotions" specifier points out additional traits like thrill seeking, fearlessness, and insensitivity to punishment. These individuals may be more aggressive for "instrumental gain." Traits fitting this specifier are more likely to present in childhood-onset.
- Research shows that callous and unemotional individuals with CD may have a slightly more severe form of the disorder and a different treatment response. Multiple information sources are necessary to assess these criteria, as those who meet it may be less likely to report such behavior.

Source: APA, 2013.

The *DSM-5* is a manual for assessment and diagnosis of mental health disorders and does not include information for treatment of any disorder. In the future, more evidence supporting treatments of disorders with *DSM-5* classifications will be available as clinical studies utilizing *DSM-5* criteria are conducted. As a result, this *Collection* will reference studies that utilize *DSM-IV* diagnostic criteria to explain symptoms and treatments.

# **Categories**

The *DSM-5* criteria for disruptive, impulse-control and conduct disorders are outlined in the paragraphs that follow.

# Oppositional Defiant Disorder (ODD)

The information in the following paragraph is from Gathright and Tyler (2014). Four refinements have been made to the criteria for ODD. First, symptoms are now grouped into three types: angry/irritable mood, argumentative/defiant behavior, and vindictiveness. This change highlights that the disorder reflects both emotional and behavioral symptomatology. Second, the exclusion criterion for conduct disorder has been removed. Third, given that many behaviors associated with symptoms of ODD occur commonly in normally developing children and adolescents, a note has been added to the criteria to provide guidance on the frequency typically needed for a behavior to be considered symptomatic of the disorder. Fourth, a severity rating has been added to the criteria to reflect research showing that the degree of pervasiveness of symptoms across settings is an important indicator of severity.

Youth must demonstrate at least four of the eight following behaviors for at least six months with at least one individual who is not a sibling to meet criteria for a diagnosis of ODD:

#### Angry/irritable mood

- 1. Often loses temper
- 2. Often angry or resentful
- 3. Often touchy or easily annoyed

#### Argumentative/defiant behavior

- 4. Often argues with authority figures or adults
- 5. Often actively defies or refuses to comply with adult's requests or rules
- 6. Often deliberately annoys others
- 7. Often blames others for his or her mistakes or misbehavior

#### Vindictiveness

8. Has been spiteful or vindictive at least twice within the past six months (APA, 2013)

Oppositional behaviors often manifest in the home setting and with adults the youth knows well. Behaviors may or may not be present in the school and/or community settings, and thus may not be present in the mental health professional's office (APA, 2013). The severity of the disorder is indicated by the number of settings in which the symptoms are present (APA). In addition to the presence of the prerequisite number of symptoms, significant distress or impairment in functioning must also be present in order to make a diagnosis of ODD. These behaviors cannot occur solely during the course of a psychotic or depressive episode or be due to bipolar disorder or substance abuse. ODD can only be diagnosed when the criteria for disruptive mood dysregulation disorder are not met (APA).

# Conduct Disorder (CD)

Children and adolescents with CD exhibit persistent and critical patterns of misbehavior. Like children with ODD, youth with CD may have an issue with controlling their tempers; however, these youth also violate the rights of others (Center for the Advancement of Children's Mental Health at Columbia University, 2000). Behaviors exhibited by children with CD include aggression towards people and/or animals, destruction of property, deceitfulness, theft, and serious violation of rules (Murphy, Cowan, & Sederer, 2001). The *DSM-5* describes the actions of someone with CD as "poorly controlled behaviors that violate the rights of others or that violate major societal norms . . . as a result of poorly controlled emotions such as anger" (APA, 2013).

The criteria for CD are that a child must exhibit three of the following 15 symptoms in the past twelve months, with one being present in the past six months:

# Aggression to people and animals

- 1. Often bullies, threatens, or intimidates others
- 2. Often initiates physical fights
- 3. Has used a dangerous weapon that can harm others
- 4. Has been physically cruel to others
- 5. Has been physically cruel to animals
- 6. Has stolen while confronting a victim
- 7. Has forced someone into sexual activity

#### Destruction of property

- 8. Has deliberately set fires with intention to cause serious damage
- 9. Deliberately destroyed the property of others

#### Deceitfulness or theft

- 10. Broken into someone else's house or car
- 11. Often lies to obtain goods or favors, or to avoid obligations
- 12. Steals items of a nontrivial value without confronting the victim

#### Serious violations of rules

- 13. Stays out at night despite parental objections (beginning before age 13)
- 14. Has run away from home at least twice for an extended period of time
- 15. Often truant from school (beginning before age 13) (APA, 2013)

These disturbances must cause clinically significant impairment in social, academic, or occupational functioning (APA, 2013). If the youth is 18 years of age or older, criteria are not met for antisocial personality disorder.

The *DSM-5* notes that CD can appear as early as the preschool years, with ODD a common premorbid condition that may progress to CD. Middle childhood to middle adolescence is the

time frame in which CD most often manifests (APA, 2013). CD is categorized into three types, according to the age at which symptoms of the disorder first occur. These types are listed below.

- **Childhood-onset CD** occurs when the youth shows one symptom characteristic of CD prior to age 10.
- Adolescent-onset CD occurs when the adolescent shows no signs of CD before age 10.
- **Unspecified-onset CD** means the individual meets the criteria for a diagnosis of CD but there is not enough information available to determine whether the onset of the first symptom was before or after age 10.

Youth diagnosed with childhood-onset CD are typically male, often display physical aggression, have disturbed peer relationships, and may have had ODD during early childhood. These youth typically develop full criteria for CD before they reach puberty. These children may have concurrent ADHD or other neurodevelopmental difficulties (Braithwaite et al., 2011; APA, 2013). Some may also have limited prosocial emotions. Children with this specific type of conduct disorder are often described as callous and unemotional (APA, 2013).

In adolescent-onset CD, adolescents are less likely to display aggressive behaviors than youth in the first subtype. They will also have more normal peer relationships and are less likely to develop adult antisocial personality disorder (APA, 2013). Unlike childhood onset, which affects more males than females, adolescent-onset CD is more balanced between males and females (APA).

Children and adolescents diagnosed with CD have more difficulty in areas of academic achievement, interpersonal relationships, drugs, and alcohol use (Boesky, 2002). They also are often exposed to the juvenile justice system because of their delinquent or disorderly behaviors. For example, Ferguson and Horwood, (as cited in Boesky), found that 90 percent of children with three or more CD symptoms at age 15 self-reported that they were frequent offenders a year later, compared to 17 percent of children with no CD symptoms. In addition, according to Murphy, Cowan, and Sederer (2001), 25 to 40 percent of children with CD have adult antisocial personality disorder later in life.

# Intermittent Explosive Disorder (IED)

Intermittent explosive disorder (IED) involves impulsive or anger-based aggressive outbursts that begin rapidly and have very little build-up (APA, 2013). The outbursts often last fewer than 30 minutes and are provoked by minor actions of someone close, often a family member or friend. The aggressive episodes are generally impulsive and/or based in anger rather than premeditated. They typically occur with significant distress or psychosocial functional impairment.

Aggressiveness must be "grossly out of proportion" to the provocation and accompanying psychosocial stressors (APA, 2013). The recurrent outbursts are neither premeditated, nor are they to achieve an outcome. Thus, outbursts are impulsive or based in anger, and are not meant to intimidate or to seek money or power. Finally, the outbursts must cause the individual

considerable distress, impair his or her occupational or interpersonal functioning, or be associated with financial or legal consequences.

The *DSM-5* now includes two separate criteria for types of aggressive outbursts. The first is characterized by episodes of verbal and/or non-damaging, nondestructive, or non-injurious physical assault that occur, on average, twice weekly for three months (APA, 2013). These could include temper tantrums, tirades, verbal arguments/fights, or assault without damage. This criterion includes high frequency/low intensity outbursts (APA).

The second criterion is characterized by more severe destructive/assaultive episodes that are more infrequent and occur, on average, three times within a twelve-month period (APA, 2013). These could be destroying an object without regard to its value or assaulting a person or an animal. This criterion includes high-intensity/low-frequency outbursts.

The following is a summary of these new *DSM-5* diagnostic criteria:

Diagnosis requires a failure to control aggressive impulses manifested by either:

- Verbal aggression like temper tantrums, tirades, arguments or fights; or physical aggression toward people, animals, or property.
  - This aggression must occur, on average, twice per week for three months.
  - The physical aggression does not damage or destroy property, nor does it physically injure people or animals.

or

- Within 12 months, three behavioral outbursts resulting in:
  - Damage or destruction of property, and/or
  - Physical assault that physically injures people or animals.

The *DSM-5* limits diagnosis of IED to individuals at least six years old or older, or who are at the equivalent developmental level. Children should not be diagnosed with IED if their impulsive and aggressive outbursts occur in the context of an adjustment disorder (APA, 2013). Additionally, the outbursts cannot be better explained by or attributable to another disorder.

#### **Pyromania**

The essential feature of pyromania is the deliberate and purposeful setting of fires (APA, 2013). It involves multiple episodes. The symptoms of this disorder include:

- Deliberately and purposefully setting a fire more than one time.
- Tension or emotional arousal being present before the act of setting the fire.
- Having a fascination with, interest in, curiosity about, or attraction to fire and its uses and consequences.

- Feeling pleasure, relief, or gratification when setting fires or when seeing the aftermath of a fire or the damage it caused.
- The fires are not set for monetary gain, to cover up criminal activity, to express anger or vengeance, in response to any hallucinations or delusions, or as a result of impaired judgment (from another disorder or substance).
- The firesetting is not better explained by CD, a manic disorder, or antisocial personality disorder.

Pyromania as a primary diagnosis appears to be very rare. In people incarcerated for repeated firesetting, only about 3 percent meet all the symptoms for pyromania. For more information on this disorder, please refer to the Juvenile Firesetting section of this *Collection*.

# Kleptomania

Kleptomania involves the impulsive and unnecessary stealing of things that are not needed (APA, 2013). Individuals may hoard the things they steal, give them away, or even return them to the store. The disorder is not about the objects stolen; it is about the compulsion to steal and the lack of self-control over this compulsion. Females with kleptomania outnumber males at a ratio of three to one (APA).

Kleptomania typically follows one of three patterns of stealing: 1) brief episodes of stealing with intermittent and long periods of remission, 2) longer periods of stealing with brief periods of remission, or 3) chronic and continuous episodes of stealing with only minor fluctuation in frequency (APA, 2013). Kleptomania is very rare, with a prevalence rate of 0.3 to 0.6 percent in the general population. Accordingly, it will not be discussed in this section of the *Collection*.

#### Other Specified Disruptive, Impulse-Control, and Conduct Disorder

A diagnosis of other specified disruptive, impulse-control and conduct disorder is available when patterns of behavior do not fit the criteria for ODD or CD, yet present significant disruption and impairment in functioning, and thus require intervention (APA, 2013). The specific reason for the diagnosis, such as "recurrent behavioral outbursts of insufficient frequency," must be included (APA).

In the *DSM-IV-TR*, symptoms and behaviors for this disorder were included in the diagnosis of disruptive behavior disorder, not otherwise specified (DBDNOS).

# Unspecified Disruptive, Impulse-Control, and Conduct Disorder

Another alternative diagnosis is unspecified disruptive, impulse-control and conduct disorder. It is diagnosed when the diagnosing clinician does not specify the reason the criteria are not met for a specific diagnosis. This often occurs when there is insufficient information for a specific diagnosis, such as an emergency room visit (APA, 2013).

In the *DSM-IV-TR*, symptoms and behaviors for this disorder were included in the diagnosis of disruptive behavior disorder, not otherwise specified (DBDNOS).

#### **Prevalence**

Prevalence of disruptive, impulse-control, and conduct disorders varies by disorder. Figure 2 outlines the prevalence rates for CD, ODD, and IED, the three disorders in this chapter more commonly found in youth.

#### Figure 2

# Prevalence of Conduct Disorder (CD), Oppositional Defiant Disorder (ODD), and Intermittent Explosive Disorder (IED)

**CD** occurs in between two and 10 percent of the population, with a median prevalence rate of 4 percent. Prevalence rates increase from childhood to adolescence and are higher in males than in females.

**ODD** occurs between one and 11 percent of the population, though the average prevalence estimate is around 3.3 percent. It may be more prevalent in males, with a ratio of approximately 1.4:1 prior to adolescence. This prevalence does not consistently continue into adolescence or adulthood.

**IED** occurs in approximately 2.7 percent of the population and is more prevalent among individuals younger than 35-40 years.

Source: APA, 2013.

The Centers for Disease Control and Prevention employed the National Survey of Children's Health (NSCH) to provide a combined prevalence estimate for ODD and CD. In 2007, parent-reported data asking about prior diagnoses and conditions identified 4.6 percent of children aged 3 to 17 years with ODD or conduct disorder. An estimated 3.5 percent had a current condition. Boys were twice as likely as girls to have these conditions. Age was associated with an increased reporting of ODD and CD (Nock et al., 2007).

#### **Causes and Risk Factors**

The majority of the research on the causes of disruptive, impulse-control, and conduct disorders focuses on CD or on CD and ODD combined (AACAP, 2007). As with most psychiatric disorders, there is no single cause of these disorders. Rather, they arise out of a complex combination of risk and protective factors related to biological and environmental/social influences (AACAP). These risk factors, which are outlined in the following paragraphs, are believed to build gradually upon each other as the child develops (AACAP).

#### **Biological Factors**

Researchers agree that there is a strong genetic and biological influence on the development of disruptive, impulse-control, and conduct disorders. These and related behavioral disorders (e.g., ADHD, substance use disorders, and mood disorders) tend to cluster in families (AACAP, 2007).

Research has consistently found that youth with disruptive, impulse-control, and conduct disorders have an underaroused baseline (e.g., low resting-heart rate) (Mawson, 2009). Several theories have tried to explain why underarousal may be associated with increased behavior problems. Some researchers suggest that underarousal results in sensation-seeking and perhaps in disruptive behaviors to maintain optimal arousal (Esyneck, 1997). Others have suggested that the underarousal results in an under-reaction of guilt or anxiety, which would otherwise inhibit these behaviors in typically developed individuals (van Goozen et al., 2004).

Additional biological factors including reduced basal cortisol reactivity and abnormalities in the prefrontal cortex and amygdala. Studies concerning these biological factors do not separate ODD from CD, so it is unclear if there are specific markers to either disorder (APA, 2013). The *DSM-5* points out that neuroimaging can show structural and functional differences in the frontotemporal-limbic connections in the ventral prefrontal cortex and amygdala; however, these findings cannot diagnose CD (APA).

Children with ODD often have parents with mood disorders, while children with CD often have parents with antisocial behavior (Searight, Rottnek, & Abby, 2001). Parents of children with CD are more likely to be depressed, to have issues of substance use, and/or to have antisocial personality traits (Searight, Rottnek, & Abby).

# **Psychological Factors**

Attachment theories have not been consistently confirmed in studies of disruptive, impulse-control, and conduct disorders (AACAP, 2007). Researchers have studied the relationship between these disorders and unresponsive parenting or impaired attachment between the child and the caregiver. However, empirical findings have been inconsistent (AACAP). Youth with disruptive, impulse-control, and conduct disorders consistently exhibit deficiencies in social processing and problem-solving. Specifically, they tend to miss social cues, attribute hostile intentions to the behaviors of others, have difficulty formulating solutions to social problems, and expect reinforcement from aggressive behaviors (AACAP).

Incidence of CD is increased in children with biological or adoptive parents and family members who also have CD or who have substance use disorder and/or depressive or bipolar disorders. Incidence of CD is also increased in children who have biological parents who have schizophrenia or ADHD. Uniquely, childhood-onset CD is particularly present comorbid with other familial disorders, and this does not present similarly in any other mental disorder (APA, 2013).

#### Social Factors

Several social factors have been associated with the development of disruptive, impulse-control, and conduct disorders, including poverty, lack of structure, community violence, and dysfunctional family environment. Youth who are neglected through lack of parental supervision and positive parenting behaviors and/or who experience harsh treatment, including child abuse, are at higher risk (AACAP, 2007). Those with deviant peer associations are also more likely to meet the criteria for these disorders. This may be because youth can learn deviant behaviors from

others and can have their negative behavior patterns reinforced in deviant relationships. Youth with deviant peer relationships may experience poorer treatment outcomes (AACAP).

The *DSM-5* notes that children and adolescents are more likely to have ODD in families where child care is disrupted by different caregivers or in families with "harsh, inconsistent or neglectful child-rearing practices" (APA, 2013). Social predictors outside of the family include peer rejection, delinquent peer groups, and a violent neighborhood (APA).

# Comorbidity

Studies of the comorbidity rates for ODD have estimated that 14 percent to 40 percent of youth have comorbid ADHD, and 9 percent to 50 percent have a comorbid anxiety or depressive disorder (Angold, Costello, & Erkanli, 1999; Riley, Amhed, & Locke, 2016). The *DSM-5* allows for a comorbidity of ODD and CD, and it specifies that ADHD and ODD are common in those with CD (APA, 2013). Studies indicate that the majority of children with ODD do not develop CD, but ODD is usually present as a forerunner to childhood-onset CD (AACAP, 2007). Research suggests that early intervention and treatment of ODD may avert the development of CD (Murrihy, Kidman, & Ollendick, 2010).

While some characteristics of ODD and CD overlap, there are important distinctions (Searight, Rottnek, & Abby, 2001). Youth with ODD do not typically display significant physical aggression and may be less likely to have problems with the law (Searight, Rottnek, & Abby). Moreover, because ODD is seen as a disorder of noncompliance and CD involves the violation of another's rights, it is helpful to view these mental health disorders as two points on a continuum, rather than as two separate mental health disorders.

Symptom severity and treatment prognosis are generally influenced by the type of comorbid conditions. For example, youth with comorbid ADHD and ODD typically display more aggressive behaviors, experience greater academic difficulties, and are rejected by peers more often than youth with ADHD alone (AACAP, 2007). Furthermore, youth with both ADHD and ODD are more likely to transition to a diagnosis of CD (AACAP; APA, 2013). Several studies have documented a strong association between disruptive, impulse-control, and conduct disorders and adolescent substance use, particularly in the face of treatment failures (AACAP). The *DSM-5* points out this comorbidity with substance use and notes that it is unclear whether the association is independent of the comorbidity with CD (APA).

Increases in oppositional and antagonistic behaviors are somewhat typical of the onset of adolescence. Youth with autism spectrum disorder, anxiety, or depression may also be more likely to exhibit these symptoms (AACAP, 2007). Clinicians, therefore, should give careful consideration to determining whether oppositional behaviors represent a true comorbid condition or are manifestations of typical development or of a primary mental health disorder.

Connor (2002) found that language and learning disorders are a common precursor to disruptive, impulse-control, and conduct disorders. Youth with CD are more likely to show deficiencies in academics and a variety of cognitive processes. There is a strong relationship between CD, academic failure, and learning disabilities (Tynan, 2010). Academic failure, particularly in

reading and other verbal skills, may justify the diagnosis of a learning or communication disorder (APA, 2013).

Gender and age are also crucial factors in determining and diagnosing comorbid conditions in youth with CD. Loeber et al. (2000) conducted a literature review of the co-morbidity of CD. Their review suggested a higher risk for adolescent females with CD and a relatively predictable association between CD and comorbid conditions. Adolescent females are also more typically at risk for anxiety and depression.

IED is frequently comorbid with depressive, anxiety, and substance use disorders. Additionally, antisocial personality disorder and borderline personality disorder frequently co-occur with IED. ADHD and other disorders involving disruptive behaviors can also increase the risk of IED development (APA, 2013).

#### Assessment

The accurate diagnosis of disruptive, impulse-control, and conduct disorders requires an assessment involving at least two different methods, such as behavior rating scales from multiple informants and structured diagnostic interviews (Christophersen & Mortweet, 2001). Interviews typically focus on the family's history and the caregivers' child-rearing practices. After interviewing the child and parents, the provider should interview teachers and evaluate the course of the child's development, including conducting a review of school records. Particular attention should be paid to any oppositional or aggressive behavior that is not age-appropriate. In the course of assessment, the mental health provider may also identify co-occurring disorders.

For a diagnosis of ODD, a pattern of negative, hostile, and defiant behavior must be present. This may or may not be accompanied by a negative or irritable mood (APA, 2013). ODD frequently occurs prior to presentation of childhood-onset CD (APA). To make a diagnosis of CD, the provider must ascertain whether the child or adolescent has shown at least three major symptoms in the past twelve months, with one of the symptoms having occurred in the last six months (APA). Individuals with CD are likely to underreport their symptoms, so clinicians must often rely on additional informants (APA).

A functional analysis of the child's behavior will not only assist in making an appropriate diagnosis, but also aid in developing an effective treatment plan (Mash & Terdal, as cited in AACAP, 2007). This involves identifying antecedents and consequences of the child's problematic behavior through a parent interview and/or direct observation in an environment where the behavior occurs. The functional analysis may help determine whether caregivers are inadvertently reinforcing negative behaviors or if the child lacks appropriate emotion regulation skills.

Table 1 lists the suggested assessment tools for disruptive, impulse-control, and conduct disorders.

Table 1
Suggested Assessment Tools for
Disruptive, Impulse-Control, and Conduct Disorders

Name of Measure	Measure Type	Who Completes	What Is Learned
Washington University version of the Kiddie-Schedule for Affective Disorders and Schizophrenia	Clinical interview	Clinician with youth and parent	Diagnosis
The Children's Interview for Psychiatric Syndromes (ChIPS)	Clinical interview	Clinician with youth and parent	Diagnosis
NIMH Diagnostic Interview Schedule for Children-IV (NIMH DISC-IV)	Clinical interview	Parent	Diagnosis
Achenbach System of Empirically Based Assessment (ASEBA)	Behavior checklist	Parent, youth, teacher	Syndrome scale scores and competence scores
Child Behavior Checklist (CBCL)	Behavior checklist	Parent, youth, teacher	Syndrome scale scores and competence scores
Youth Self-Report (YSR)	Behavior checklist	Parent, youth, teacher	Syndrome scale scores and competence scores
Teacher Report Form (TRF)	Behavior checklist	Parent, youth, teacher	Syndrome scale scores and competence scores
Strengths & Difficulties Questionnaire	Behavior checklist	Parent, youth, teacher	Four problem scales and one "strengths" scale
Behavior Assessment System for Children-2 <sup>nd</sup> edition (BASC)	Behavior checklist	Parent, youth, teacher	Syndrome scale scores and adaptive scores

Sources: Achenbach & Rescorla, 2001; Reynolds & Kamphaus, 2004; Gathright & Tyler, 2014.

#### **Treatments**

Although ODD, CD, and IED are considered separate diagnoses, the treatment principles for these disorders are very similar. Individualized treatment plans should be developed to address the particular problems and severity of each child and family situation. A summary of treatments are outlined in Table 2 and discussed in the paragraphs that follow.

Table 2
Treatments for Disruptive, Impulse-Control, and Conduct Disorders

What Works				
Assertiveness training	School-based group treatment for middle- school youth			
Parent management training (PMT)  • Helping the Noncompliant Child  • Incredible Years  • Parent-child interaction therapy  • Parent MT to Oregon model  • Positive parenting program	PMT programs focus on teaching and practicing parenting skills with parents or caregivers			
Multisystemic therapy (MST)	MST is an integrative, family-based treatment for youth with serious antisocial and delinquent behavior. Interventions last 3-5 months and focus on improving psychosocial functioning			
Cognitive behavioral therapy (CBT) • Problem-solving skills training • Anger control training	CBTs emphasize problem-solving skills and anger control/coping strategies			
CBT & parent management training	Combines CBT and PMT			
What Seems to Work				
Multidimensional treatment foster care	Community-based program alternative to institutional, residential, and group care placements for use with severe chronic delinquent behavior; foster parents receive training and provide intensive supported treatment within the foster home			
Not Adequately Tested				
Atypical antipsychotics medications	Risperidone (Risperdal), quetiapine (Seroquel), olanzapine (Zyprexa), and aripiprazole (Abilify); limited evidence for effectiveness in youth with ID or ASD			
Stimulant or atomoxetine	Methylphenidate, d-Amphetamine, atomoxetine; limited evidence when comorbid with primary diagnosis of ADHD			
Mood stabilizers	Divalproex sodium, lithium carbonate; limited evidence wher comorbid with primary diagnosis of bipolar disorder			
Selective serotonin reuptake inhibitors (SSRIs)	Limited evidence when comorbid with primary diagnosis of depressive disorder			
What Does Not Work				
Boot camps, shock incarcerations	Ineffective at best; can lead worsening of symptoms			
Dramatic, short-term, or talk therapy	Little to no effect as currently studied			

Sources: Lochman, Barry & Pardini, 2003; Huey & Rank, 1984; McMahon & Forehand, 1981; Webster-Stratton & Reid, 2003; Chamberlain & Smith, 2003; Henggeler & Lee, 2003; Brinkmeyer & Eyberg, 2003; Patterson, Reid, Jones & Conger, 1975; Sanders, 1999; Kazdin, 2003; McCloskey, Noblett, Deffenbacher, Gollan, Coccaro, 2008; Kazdin et al., 1989; Kazdin, Siegel & Bass, 1992; Block, 1978; AACAP, 2007; Eyeberg, Nelson & Boggs, 2008; Sanders, 1999; Children's Mental Health Ontario, 2001; Tynan, 2010; Garthright & Tyler, 2014; & Capaldi & Eddy, 2015.

# **Psychosocial Treatments**

Eyberg, Nelson & Boggs (2008) identified 16 evidence-based treatment programs for disruptive, impulse-control, and conduct disorders. Nearly all employ parent behavior management training as the primary intervention. The key strategies of these approaches include the following:

- Identification and reduction of positive reinforcement of structured behavior;
- Increased reinforcement of prosocial and compliant behavior;
- Utilization of nonviolent and consistent discipline for disruptive behaviors; and
- Emphasis on predictability and immediacy of parental contingencies (AACAP, 2007; Capaldi & Eddy, 2015).

The following is taken from Capaldi and Eddy (2015). There are two classes of evidence-based interventions for treatment of CD and ODD that are shown to be effective: parent management training and social skills training, in which youth are taught cognitive and behavioral techniques and strategies that are useful in solving interpersonal problems. Over the past 50 years, a variety of these programs have been shown to have a positive effect. A separate meta-analysis of psychosocial interventions showed that those that included a parent component, either alone or in combination with other intervention components, were most likely to reduce problem behaviors (Epstein et al., 2015). These findings suggest the importance of working with parents or caregivers when attempting to reduce disruptive child behaviors.

Multisystemic therapy (MST) is an individualized case management program that incorporates many aspects of parent management and child social skills training for youth with serious behavior disorders who are at risk for out-of-home placement (Henggeler et al., 2009). MST attempts to intervene with the multiple factors that can contribute to antisocial behavior at the individual, family, and broader social levels, including peer, school, and neighborhood factors (Capaldi & Eddy, 2015). Trained clinicians identify strengths in each youth's social network and capitalize on these to promote positive change. By helping both parents and youth to manage their lives more effectively, the need for out-of-home placement may be eliminated. Treatment is designed in collaboration with the family, and therapists have low caseloads and are available around the clock. The average duration of treatment is four months; during this time, therapists work very closely (e.g., multiple times per week in the home and community) with youth and families (Capaldi & Eddy). In a variety of studies, reductions of 25 to 70 percent in long-term rearrest rates and of 47 to 64 percent in out-of-home placements have been achieved, and positive improvements in youth and family functioning have been observed for several years following intervention (Capaldi & Eddy).

The only available study on psychosocial treatments for IED found that patients receiving active cognitive-behavioral therapy (CBT) or group therapy showed significant improvements compared with waitlist controls. These improvements spanned several target symptoms of IED (Grant & Leppink, 2015).

Severe and persistent cases of ODD that develop into CD may require an alternative placement when the safety of the youth and/or those around him or her are in jeopardy (AACAP, 2007). Youth may require out-of-home placement when they require crisis management services or when their family is unable or unwilling to collaborate with treatment. When considering day

treatment, residential treatment, or hospitalization, the least restrictive setting should be selected for the shortest possible time to ensure safety and progress (AACAP). Other placements that may be considered are therapeutic foster care or respite care.

# Pharmacological Treatments

Pharmacological treatments for disruptive, impulse-control, and conduct disorders have not been well-studied (AACAP, 2007). Stanford, Howard, and the AACAP Workgroup on Juvenile Impulsivity and Aggression (Connor et al., 2006) recommend that medication only be used to treat youth with ODD or CD when evidence-based psychosocial treatments have failed. Medication should not be the sole treatment for CD or ODD (AACAP). In addition, effect sizes for psychosocial interventions are larger than effect sizes for psychotropic medication with this population.

In a separate review of evidence-based treatments for CD and ODD, a variety of medications have been examined as adjuncts to treatment (Capaldi & Eddy, 2015). In cases of severe aggressive behavior, for example, lithium or one of the neuroleptics (also known as antipsychotics) may be prescribed. However, the neuroleptics have more numerous and serious side effects. Again, even in extreme cases, medication is not recommended as either the sole or the primary treatment (Capaldi & Eddy).

Despite a lack of research, atypical antipsychotics are the most commonly prescribed medication for aggression associated with ODD and CD (AACAP, 2007). The largest body of research suggests that risperidone has some efficacy with ODD. However, risperidone usually is considered a second- or third-line option because it has been associated with adverse effects in children and adolescents and requires caution in younger populations, despite its potential efficacy (Grant and Leppink, 2015).

Medications may also be helpful when there are co-occurring disorders, making it more likely that the youth will be able to participate in and benefit from intervention strategies (Capaldi & Eddy, 2015). Pharmacological interventions may be helpful, for example, when a child or adolescent has a disorder that is responsive to medication, such as ADHD or bipolar disorder. ODD has a high comorbidity rate with ADHD, and medications often prescribed for ADHD, such as stimulants and atomoxetine, may help improve oppositional behaviors as well (AACAP, 2007). Stimulants have also improved ODD symptoms in randomized trials (Grant and Leppink, 2015). There is limited research suggesting that mood stabilizers or selective serotonin reuptake inhibitors (SSRIs) may be helpful when there is a co-occurring mood disorder, such as bipolar or major depressive disorder (AACAP). Alpha-2 agonists (clonidine and guanfacine) have shown some efficacy in treating ODD but have not been studied extensively (Grant and Leppink).

It is important to note that aggression and oppositional behaviors can reflect temporary environmental changes. Utilizing medication during these circumstances may result in misattribution of improvement to the medication, rather than environmental stabilization, and thus result in an unnecessary risk of side effects. In all cases, medications should be started only after an appropriate baseline of symptoms or behaviors has been obtained and only in conjunction with psychosocial treatment (AACAP, 2007).

# **Unproven Treatments**

Research indicates that treatment of disruptive, impulse-control, and conduct disorders should be delivered with enough frequency and duration to produce the desired treatment outcomes (Children's Mental Health Ontario, 2001). There are several treatments that have been untested, proven ineffective, or proven to be harmful. Scare tactic approaches (e.g., boot camps, shock incarcerations) are ineffective and can even worsen symptomatic behaviors by heightening a fear-aggression reaction and/or modeling of even more deviant behaviors (Capaldi & Eddy, 2015; AACAP, 2007). Boot camps have consistently demonstrated good initial results but long-term declines, such as higher arrest rates and more serious crimes committed (Tynan, 2010). Moreover, group treatment may also have possible negative adverse effects. Poor long-term outcomes following this treatment may be due to group reinforcement of negative or criminal activity, accompanied by lack of family or community change (Capaldi & Eddy; Tynan). Individual psychotherapy as a single treatment also has not proven effective for CD, although individual sessions may facilitate treatment compliance (Tynan). Dramatic, one-time, time-limited, or short-term interventions are also ineffective treatment approaches (AACAP).

#### **Cultural Considerations**

The *DSM-5* states that ODD in children and adolescents is relatively consistent across countries that differ in race and ethnicity (APA, 2013). ODD and CD are more prevalent among adolescents from families with low socio-economic status (Loeber et al., 2000). CD is more common in neighborhoods characterized by social disorganization and high crime rates (Loeber et al.). More research is needed to assess the differences between CD and ODD in rural and urban environments, given that results from current research are mixed and the poor prognosis of CD is associated with urban areas (Loeber et al.). In fact, the *DSM-5* cautions against misdiagnosing CD in particularly dangerous areas where disruptive behavior is viewed as normal, including high-crime areas and war zones (APA, 2013).

Research on treatments for disruptive, impulse-control, and conduct disorders has adequate representation of African-American children, suggesting that treatments are generally as effective with those populations as for Caucasian children (Eyberg et al., 2008). Latino children and children from other minority groups, however, have been under-represented in most studies of treatments. In the absence of research on cultural-specific practices, clinicians should take care to ensure that treatment goals and strategies are in sync with cultural beliefs and practices.

When compared to the United States, IED is less prevalent in some regions, like Asia and the Middle East, as well as countries like Romania and Nigeria. The *DSM-5* notes that either the explosive actions that characterize the disorder are not discussed during questioning or are less likely to occur because of cultural expectations (APA, 2013).

Males with CD are more likely to fight, steal, vandalize, and have discipline issues in school. Males are likely to be physically aggressive and harm their social relationships, which is known as "relational aggression." Females, on the other hand, are more likely to lie, skip school, run away, abuse substances, and get involved in prostitution. Females are more likely to harm their social relationships than be physically aggressive (APA, 2013).

#### Overview for Families

A child being disagreeable is normal. Oppositional behavior is a serious concern only if it is extreme when compared with children of similar age and developmental level, and if it affects the child's social, family, and academic life (AACAP, 2013a). Defiant and oppositional behavior can manifest itself as oppositional defiant disorder (ODD), the more severe conduct disorder (CD), or intermittent explosive disorder (IED).

ODD manifests as a pattern of hostile behavior, including but not limited to:

- Frequent temper tantrums
- Excessive arguing with adults
- Active defiance and refusal to comply with adult requests and rules
- Deliberate attempts to annoy or upset people
- Blaming others for his or her mistakes or misbehavior
- Often being touchy or easily annoyed by others
- Frequent anger and resentment
- Mean and hateful talking when upset
- Spiteful attitude and revenge seeking (AACAP, 2013a)

The symptoms of CD are much more severe, including but not limited to:

- Abnormal aggression to people and animals
  - Steals from victim while confronting them
  - Has used a dangerous weapon to harm others
  - Forces someone into sexual activity
- Destruction of property
- Deceitfulness, lying, or stealing
- Serious violations of rules (AACAP, 2013b)

While the symptoms of both ODD and CD include conduct problems that bring the child into conflict with adults, ODD is less severe and does not include aggression toward people or animals, destruction of property, or patterns of theft (APA, 2013).

The symptoms of IED include short, impulsive or anger-based aggressive outbursts that begin rapidly and have very little build-up (APA, 2013). The aggressive episodes are generally impulsive and/or based in anger rather than premeditated.

Children diagnosed with IED display:

- Verbal or physical aggression that occurs, on average, twice per week for three months but does not result in damage or injury to people or animals, **or**
- Behavioral outbursts that occur three or more times a year that do result in damage or injury to people or animals

Disruptive disorders often co-occur with other disorders such as ADHD. CD can also be a result of brain damage or past child abuse (AACAP, 2013a; AACAP, 2013b).

Treating children with these disorders can be complex. Any child exhibiting symptoms should have a comprehensive evaluation. Evaluators should also look for other disorders, as they are often present.

# **Resources and Organizations**

#### American Academy of Child & Adolescent Psychiatry (AACAP)

Conduct Disorder Resource Center

http://www.aacap.org/aacap/Families\_and\_Youth/Resource\_Centers/Conduct\_Disorder\_Resource\_Center/Home.aspx

#### **American Psychiatric Association (APA)**

https://www.psychiatry.org/

# American Psychological Association (APA)

http://www.apa.org/

# **Association of Behavior and Cognitive Therapies**

http://www.abct.org/Home/

# Mental Health America (MHA) (formerly National Mental Health Association)

Fact Sheet on Conduct Disorder

http://www.mentalhealthamerica.net/conditions/conduct-disorder

Oppositional Defiant Disorder Resource Center

http://www.aacap.org/aacap/Families\_and\_Youth/Resource\_Centers/Oppositional\_Defiant\_Disorder\_Resource\_Center/Home.aspx

#### Society of Clinical Child and Adolescent Psychology

https://www.clinicalchildpsychology.org/

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# Substance Use Disorders

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#### Introduction

It is not uncommon for adolescents to experiment with a variety of substances, both legal and illegal. However, drug and alcohol use is a leading cause of morbidity and mortality among adolescents, and experimentation can lead to substance use disorder. An estimated 1.2 million adolescents aged 12 to 17 had a substance use disorder in 2015, which represents 5.0 percent of adolescents, or about 1 in 20 adolescents (Center for Behavioral Health Statistics and Quality, 2016). In addition, in 2015, 5.3 million young adults aged 18 to 25 had a substance use disorder.

Studies have shown that children who experiment with substances at a young age are more likely to use other drugs later in life. Data from the Substance Abuse and Mental Health Services Administration (SAMHSA) Treatment Episode Data Set (TEDS) revealed that 74 percent of adults participating in a substance abuse treatment program had initiated alcohol or drug use before the age of 17. Those who began at a very young age (11 years old or younger) were more likely to have multiple substance dependencies when compared to those who waited until they were 25 years and older (SAMHSA, 2014). These findings highlight the need to prevent drug initiation among adolescents and children or delay it for as long as possible.

# Recent Changes from the DSM-IV to the DSM-5

Information in this section is taken from the American Psychiatric Association (APA, 2013).

In 2013, the American Psychiatric Association (APA) released the fifth edition of the *Diagnostic* and *Statistical Manual of Mental Disorders* (*DSM-5*) to replace the fourth text revision (*DSM-IV-TR*). Previously, the *DSM-IV-TR* identified two separate substance use disorders. The first of

these was substance abuse, which referred to the maladaptive use of a substance and required just one criterion of maladaptive use be met over a one-year period. The second was substance dependence, which referred to physiological and/or psychological addiction and required three criterion of addictive use be met over a one-year period. The *DSM-5* collapsed these two distinct disorders into one condition, substance use disorder. Substance use disorder criteria include all symptoms in the *DSM-IV-TR* for substance abuse and substance dependence, with the exception of the removal of "recurrent legal problems" and the addition of "craving." Like the *DSM-IV-TR*, the *DSM-5*, identifies substance-induced disorders, including intoxication, withdrawal, and substance or medication-induced mental disorders.

Substance use disorders also have a severity scale, which is measured by the number of criteria met. The severity scale, as set forth in the *DSM-5*, is as follows:

- Two to three criteria indicate a **mild** disorder
- Four to five criteria indicate a **moderate** disorder
- Six or more criteria indicate a **severe** disorder

New withdrawal categories identified in the *DSM-5* include cannabis withdrawal and caffeine withdrawal.

The *DSM-5* also specifies the following remission criteria:

- Early remission entails at least three but less than 12 months without substance use disorder criteria (except craving)
- Sustained remission is defined as at least 12 months without criteria (except craving)

The *DSM-5* is a manual for assessment and diagnosis of mental health disorders and does not include information for treatment of any disorder. In the future, more evidence supporting treatments of disorders with *DSM-5* classifications will be available as clinical studies utilizing *DSM-5* criteria are conducted. As a result, this *Collection* will reference studies that utilize *DSM-IV* diagnostic criteria to explain symptoms and treatments.

#### **Categories**

*Unless otherwise cited, information in this section is taken from APA (2013).* 

Disorders collected under the title of substance-related disorders in the *DSM-IV-TR* are now collected under the name of substance-related and addictive disorders in the *DSM-5*. Specific criteria for substance abuse and substance addiction have been combined into the name of "substance use disorders."

The main evidence of the existence of a substance use disorder is the cluster of cognitive, behavioral, and physiological symptoms that reflect the persistence of use despite substance-related problems. (J. Aaron, personal communication, October 17, 2017). The symptoms of substance use disorder can be grouped into four categories: impaired control, social impairment, risky use, and pharmacological criteria.

Pharmacological criteria include tolerance and withdrawal. Tolerance is the need for larger amounts of the substance to achieve the desired intoxication effects. Withdrawal is an intense and unpleasant cluster of physiological and cognitive symptoms. Withdrawal symptoms generally vary across substances. While youth may continue substance use for many reasons, those with physiological addiction may continue their use despite negative consequences in order to either avoid or relieve withdrawal symptoms.

The specific criteria used to diagnose substance use disorder are common across the classes of substances. Substance use disorder is diagnosed when there is a problematic pattern of substance use leading to clinically significant impairment or distress, as manifested by at least two of the following, occurring within a 12-month period:

- The substance is taken in larger amounts or over a longer period than originally intended.
- There are multiple unsuccessful attempts to stop usage, despite a strong desire to do so.
- A great deal of time is spent obtaining, using, or recovering from the effects of the substance.
- The individual experiences cravings or strong desire to use the substance.
- Recurrent use results in failure to fulfill major obligations at work, school, or home.
- Use continues despite persistent social or interpersonal problems caused by use.
- Important social, occupational, or recreational activities are given up or reduced because of use.
- Use continues in situations in which use is physically hazardous.
- Use continues despite knowing one has a physical or psychological problem that is likely to be caused or exacerbated by the substance.
- Tolerance, defined as requiring a markedly increased dose to achieve the desired effect, develops.
- Withdrawal symptoms occur, which lead the individual to use the substance in order to relieve the symptoms.

The severity of substance use disorder is estimated by the number of criteria present. An estimated two or three symptoms is mild, four or five is moderate, and six or more is severe.

The *DSM-5* divides substances into the following ten classes:

- 1. Alcohol
- 2. Caffeine
- 3. Cannabis
- 4. Hallucinogens
  - Phencyclidine (PCP)
  - Other hallucinogens
- 5. Inhalants
- 6. Opioids
- 7. Sedatives, hypnotics, and anxiolytics
- 8. Stimulants
- 9. Tobacco
- 10. Other substances

Substance use disorder is a possible diagnosis in every class except caffeine. These classes are described in the paragraphs that follow.

#### Alcohol

Alcohol use disorder is characterized by a cluster of behavioral and physical symptoms, which can include withdrawal, tolerance, and craving. Withdrawal develops approximately four to 12 hours after the reduction of intake following prolonged, heavy alcohol ingestion. Once a pattern of repetitive and intense use develops, individuals with alcohol use disorder may devote substantial periods of time to obtaining and consuming alcoholic beverages. Withdrawal is unpleasant and triggers some individuals to continue consuming alcohol to avoid or reduce withdrawal symptoms. In addition, withdrawal can trigger life-threatening seizures in some people. Alcohol cravings, indicated by a strong desire to drink, can incite individuals to use alcohol in physically hazardous ways, such as while driving or swimming. Resulting damage from alcohol use disorder can include poor school performance, social and interpersonal problems, blackouts, depression, and liver disease and other serious health problems.

Studies have also shown that one form of substance abuse, binge drinking, damages the adolescent brain more than the adult brain. Examination of differences in the effects of alcohol on receptor activity in the hippocampus of adolescents and adults reveals the impact of alcohol on these age groups (White, 2004). These differences suggest that adolescents are more vulnerable than adults to the impact of alcohol on learning and memory. Heavy drinking in early or middle adolescence, with resulting cortical damage, can also lead to diminished control over cravings for alcohol and to poor decision-making (White).

#### Caffeine

Caffeine can be found in coffee, tea, caffeinated soft drinks, energy drinks and similar aids, over-the-counter analgesics and cold remedies, weight-loss aids, chocolate and, increasingly, vitamins and food products. Symptoms of caffeine intoxication include restlessness, nervousness, excitement, insomnia, flushed face, diuresis, and gastrointestinal complaints. Symptoms at higher doses include muscle twitching, rambling thoughts and speech, tachycardia or cardiac arrhythmia, periods of seemingly unlimited energy, and psychomotor agitation. These signs may not occur in those who have developed a tolerance. Caffeine withdrawal symptoms include headache with marked fatigue or drowsiness, dysphoric or depressed mood, irritability, difficulty concentrating, nausea, vomiting, or muscle pain and stiffness.

#### **Cannabis**

Cannabis, also known as marijuana, is used in several forms, including plant form and a concentrated extraction called hashish. It is typically smoked (via pipes or water pipes, in cigarette form, or in paper from hollowed out cigars) or ingested. A new intake method, called vaporizing, involves heating plant material to release psychoactive cannabinoids for inhalation. Synthetic formulations are available in pill or capsule form for medical indications such as relieving nausea and vomiting from chemotherapy or stimulating appetite in individuals with AIDS. Cannabis has also been used to control seizures in persons with epilepsy who do not respond to other interventions.

Cannabis intoxication typically begins with a "high" feeling, followed by euphoria, inappropriate laughter and grandiosity, sedation, and lethargy. Additional symptoms include short-term memory impairment, difficulty completing complex mental processes, impaired judgment, distorted sensory perceptions, impaired motor performance, and the sensation that time is passing slowly. At times, cannabis use is accompanied by anxiety, dysphoria, or social withdrawal. Physical signs develop within two hours of cannabis use, including conjunctival injection (red, bloodshot eyes), increased appetite, dry mouth, and tachycardia.

The *DSM-5* recognizes the potential of cannabis withdrawal syndrome, symptoms of which include irritability, anger or aggression, anxiety, depressed mood, restlessness, difficulty sleeping, and decreased appetite or weight loss.

Although cannabis use disorder can co-occur with other substance use disorders, this is uncommon.

# Hallucinogens

# Phencyclidine (PCP)

Phencyclidine (PCP or angel dust) and similar substances are referred to as dissociative hallucinogens. They produce feelings of separation from the mind and body in small doses, and stupor and coma can result at high doses. These substances include phencyclidine, ketamine, cyclohexamine, and dizocilpine. They are often smoked or taken orally, but they can also be snorted or injected. While these drugs are often used in an illicit manner, ketamine is also used to help treat major depressive disorder.

The primary effects of PCP last for a few hours, but the drug stays in the body eight days or more. The *DSM-5* separates PCP intoxication from intoxication by other hallucinogens. Common symptoms of PCP intoxication include disorientation, confusion without hallucination, hallucinations or delusions, catatonic-like state, and coma of varying severity.

#### Other hallucinogens

Many hallucinogens are chemically different from one another but, as a group, they produce similar perception, mood, and cognition alterations in users. These substances are typically taken orally, but they are sometimes smoked. Duration of hallucinogenic effects varies depending upon the substance taken, and some substances have a long half-life, extending the effects even further. This is important because the effects of a substance with a longer half-life persist longer than those with a shorter half-life. Tolerance may develop to hallucinogens, but hallucinogen tolerance does not create a cross-tolerance with other drug categories, such as amphetamines or cannabis.

Hallucinogen use may lead to hallucinogen persisting perception disorder, characterized by a sober individual re-experiencing perceptual disturbances. These persistent disturbances can happen either episodically or almost continually, and may last for weeks, months, or years. The disturbances are typically visual, including geometric hallucinations, false perceptions of movement in peripheral vision, intensified or flashing color, and trails of visual images.

Additional disturbances include hallucinating entire objects, experiencing positive afterimages and halos, and misperceiving the size of images.

The *DSM-5* does not include hallucinogenic withdrawal syndrome as a criteria for abuse or as a diagnosis because clinically significant withdrawal syndrome has not been consistently documented in humans. However, there is some evidence of hallucinogenic and stimulant withdrawal symptoms associated with MDMA (also called ecstasy or molly).

#### Inhalants

Inhalants are volatile hydrocarbons: toxic gases from glues, fuels, paints, and other volatile compounds. Inhalant intoxication develops during or immediately following volatile hydrocarbon substance inhalation, and the intoxication ends several minutes to several hours after inhalation. At times, inhalation is completed by inhaling substances within a closed container, like a plastic bag over the head. Inhalation may cause unconsciousness, anoxia, and death. Sudden death may also occur, often from cardiac arrhythmia or arrest or from the toxicity of the substance inhaled.

Inhalant use disorder exists when use persists even when the user knows the substance is causing serious problems. Lingering odors and peri-oral or peri-nasal rash may suggest the presence of the disorder. Medical complications like brain white matter pathology and rhabdomyolysis, in which muscle fibers break down and release into the bloodstream, is also a possible indication of inhalant use disorder.

# **Opioids**

Opioids relieve pain and induce euphoria. Some opioids are illegal, such as heroin, while others are used by medical professionals to treat pain and are available by prescription. The brain also manufactures natural opioids, which human beings naturally crave (Rosenblatt & Catlin, 2012). This natural craving, combined with the intense pleasure opioids can induce, can be a dangerous combination that can lead to abuse.

Opioid use disorder is the compulsive, prolonged self-administration of opioids for no legitimate medical purpose, or the use of opioids in great excess of what is needed to treat a medical condition. Prescription forms of opioids are sometimes acquired by falsifying or exaggerating medical conditions or by visiting several physicians for the same disorder (called "doctor shopping"). In addition, prescription opioids are sometimes easily accessible in the family home, which poses a significant risk to youth and adolescents.

Symptoms of opioid intoxication include initial euphoria followed by apathy, dysphoria, and psychomotor agitation or impairment. Impaired judgment also occurs. Most individuals with opioid use disorder have developed significant tolerance to the drugs, and discontinuation causes withdrawal symptoms. Withdrawal can also occur independently of opioid use disorder and regardless of whether use is medical or recreational. In addition, other disorders can be induced by opioid use, such as opioid-induced depressive disorder, opioid-induced anxiety disorder, opioid-induced sleep disorder, and opioid-induced sexual dysfunction.

In 2015, an estimated 276,000 adolescents aged 12 to 17 were current misusers of opioids, which corresponds to 1.1 percent of adolescents (Center for Behavioral Health Statistics and Quality, 2016). Moreover, the prescribing rates for opioids among adolescents and young adults nearly doubled from 1994 to 2007 (American Society of Addiction Medicine [ASAM], 2016). Abuse of prescription medication can lead to abuse of drugs such as heroin. In 2014, an estimated 21,000 adolescents had used heroin in the past year, an estimated 5,000 were current heroin users, and an estimated 6,000 had a heroin use disorder (ASAM).

To learn more about the risks associated with opioid medications, physicians can utilize the Updated Medication Guides available for each brand of opioid, patient counseling documents, and the Extended-Release and Long-Acting Opioid Analgesics Risk Evaluation and Mitigation Strategy (REMS) website (FDA, 2017). The FDA has also released a blueprint for prescriber education regarding extended-release/long-acting opioids. This blueprint outlines key information about different brands of opioids and contains guidance about patient assessment, initiating and managing opioid therapy, and counseling patients about the dangers of opioids (FDA).

# Sedatives, Hypnotics, and Anxiolytics

Several drug types are included in the sedatives, hypnotics, and anxiolytics category. These include benzodiazepines, benzodiazepine-like drugs, carbamates, barbiturates, barbiturate-like hypnotics, all prescription sleeping medications, and almost all prescription anti-anxiety medications. One type of substance omitted from this category is nonbenzodiazepine antianxiety medications because they are not significantly misused.

These drugs are brain depressants and act similarly to alcohol. Individuals who misuse sedatives, hypnotics, or anxiolytics typically crave the substance and may mix it with other medicines and substances. Symptoms of intoxication associated with a substance use disorder include inappropriate sexual or aggressive behavior, marked fluctuation of mood, and impaired judgment. Additionally, intoxication may include slurred speech, lack of coordination to the level of causing falls or difficulty driving, unsteady gait, cognitive impairment, and stupor or coma. Clinicians can also look for nystagmus, or fast, uncontrollable eye movements. As with all substance use disorders, impaired social or occupational functioning also results.

Tolerance and withdrawal can occur with sedative, hypnotic, or anxiolytic use and can be very significant. However, tolerance and withdrawal that occurs as a result of appropriate medical use does not meet the criteria for a substance use disorder. Sedatives, hypnotics, and anxiolytics are often prescribed to offset or alleviate effects of other substance use disorders. Nevertheless, with regular use, tolerance develops, and the affected individual must take more of the substance to reach desired effects.

Withdrawal from sedatives, hypnotics, and anxiolytics typically occurs after several weeks of use, and it is similar to alcohol withdrawal. Symptoms include increased heart and respiratory rate, elevated blood pressure or body temperature, and sweating, along with hand tremors, nausea occasionally with vomiting, insomnia, and anxiety. Another possible symptom of withdrawal is psychomotor agitation, which is unintentional motor activity manifested as fidgeting, pacing, and hand-wringing (Leventhal & Zimmerman, 2010). As many as 20 to 30

percent of individuals treated for sedative, hypnotic, or anxiolytic withdrawal may experience grand mal seizures. The time between last dose and onset of withdrawal symptoms depends upon the substance. For example, withdrawal symptoms from triazolam can begin within a few hours, while withdrawal symptoms from diazepam (which lasts much longer in the body) may take one to two days to develop.

#### **Stimulants**

Stimulants include amphetamines and amphetamine-type substances (such as cocaine, crack cocaine, and methamphetamine). Stimulants are typically taken orally, intravenously, or by being inhaled. Stimulant medications are often prescribed for obesity, attention-deficit/hyperactivity disorder (ADHD), and narcolepsy. Stimulant use disorder can develop within one week of onset of use, and tolerance occurs regardless of whether a substance use disorder develops. Stimulants stimulate the central nervous system and produce psychoactive and sympathomimetic effects. Dopamine levels increase in the brain, causing intense pleasure and increased energy or, in some cases, anxiety and paranoia. With repeated use, stimulants can disrupt the dopamine system, reducing an individual's ability to feel pleasure (National Institute on Drug Abuse [NIDA], 2014). Long term effects include panic attacks, paranoid psychosis, increased risk for heart attacks and, for intravenous users who share needles, infection with HIV (NIDA).

Withdrawal symptoms include hypersomnia (excessive daytime sleepiness or prolonged nighttime sleep), increased appetite, and dysphoria (National Institute of Neurological Disorders and Stroke (NINDS), 2013). Occasionally, vivid and unpleasant dreams will also occur, and appetite will increase. Additionally, intense depressive symptoms that resolve within one week often signal stimulant withdrawal.

#### Tobacco

Tobacco use disorder typically occurs in those who smoke or use tobacco products daily, but not in those who do not use tobacco daily or who use nicotine medications such as smoking cessation aids. Individuals who are not used to using tobacco often feel nausea and dizziness upon use, symptoms that are more pronounced with the first use of tobacco each day. Those with tobacco use disorder typically do not experience these symptoms. Most tobacco users report strong cravings when they do not use tobacco for several hours, and many tobacco users chain smoke (smoke cigarettes all day with no break between). Tobacco users may forego social events for a lack of tobacco-friendly areas.

When tobacco use is stopped, very distinct withdrawal symptoms occur. These symptoms are much stronger in users who smoke or use smokeless tobacco than in those who use nicotine medications. The symptomatic discrepancy is potentially because of the higher levels of nicotine in cigarettes and smokeless tobacco in comparison to levels in nicotine medications. People who have ceased tobacco use often experience a heart rate decline of five to 12 beats per minute and a weight increase of four to seven pounds.

#### Unknown or Other Substance Use Disorder

The *DSM-5* provides for diagnostic criteria for a substance use disorder with unknown origin unrelated to the substances listed above. The following substances meet this criterion:

- Anabolic steroids
- Nonsteroidal anti-inflammatory drugs
- Cortisol
- Antiparkinsonian medications
- Antihistamines
- Nitrous oxide
- Anyl-butyl- or isobutyl-nitirites
- Betel nut, chewed in many cultures for mild euphoria and a floating sensation
- Kava, often taken for sedation, incoordination, weight loss, mild hepatitis, and lung abnormalities
- Cathinones, which produce a stimulant effect

Unknown substance use disorder is associated with an intoxicant the individual cannot identify or with new illegal drugs that are not yet identified.

Intoxication by unknown substances is challenging to diagnose. Clinicians may ask for patient history to determine whether the youth experienced similar symptoms in the past and if the youth knows a street name for the substance.

#### **Prevalence**

The prevalence of substance use disorders varies among the substances used. Table 1 outlines the 12-month prevalence rates of substance use disorders among various populations. At this time, available prevalence rates do not capture substance use by youth younger than 12 years of age.

The following is taken from APA (2013). Recent studies indicate that there may be an increase in phencyclidine (PCP) use among 12<sup>th</sup> graders, from 1.8 percent to 2.3 percent having ever used, and from 1.0 percent to 1.3 percent having used within the past year. Of the 12<sup>th</sup> graders who have used phencyclidine, 57 percent have used it within the past 12 months. Use of ketamine in the past year is stable in 12<sup>th</sup> graders at a rate of 1.6 to 1.7 percent. The rate of hallucinogenic use is significantly higher than that of hallucinogenic abuse, with as many as 3.1 percent of 12 to 17 year olds having used hallucinogens within the past 12 months. There is no gender difference in usage rates for 12 to 17 year olds.

Monitoring the Future (MTF) is a long-term study of American adolescents, college students, and adult high school graduates through age 55. It has been conducted since 1975. Results from the 2016 study found that annual prevalence of the use of any illicit drug, excluding marijuana, was 5 percent, 10 percent, and 14 percent for youth in 8<sup>th</sup>, 10<sup>th</sup>, and 12<sup>th</sup> grades, respectively (Johnston et al., 2017). This report noted that psychotherapeutic drugs warrant special attention, given that they now make up a significantly larger part of the overall U.S. drug problem than was true over ten years ago. The survey also revealed that between 48 and 50 percent of students had tried illicit drugs by the time they left high school (Johnston et al). Alcohol remains the substance most widely used by adolescents. Despite recent declines, six out of every 10 students (61 percent) have consumed alcohol by the end of high school, and about a quarter (23 percent) have done so by 8<sup>th</sup> grade. Nearly half (46 percent) of 12<sup>th</sup> graders and one in 11 (9 percent) 8<sup>th</sup> graders in 2016 reported having been drunk at least once in their life. Among 12<sup>th</sup> graders, the annual prevalence of marijuana use was over 35 percent in 2016 (Johnston et al.).

Table 1

Prevalence Rates of Substance Use Disorders

Substance Use Disorder	Youth 12–17	Males 12–17	Females 12–17	Adults 18+	Males 18+	Females 18+
Alcohol	4.6%			8.5%	12.4%	4.9%
Cannabis	3.4%	3.8%	3.0%	1.5%	2.2%	0.8%
Caffeine		Unclear: estimates of 7% of U.S. population may experience five or more symptoms with functional impairment consistent with a diagnosis of caffeine intoxication				
Phencyclidine	0.3% have ever used			1.3%–2.9% have ever used		
Other hallucinogens	0.5%	0.4%	0.6%	0.1%	0.2%	0.1%
Inhalants	0.4%					
Opioids	1.0%			0.37%	0.49%	0.26%
Heroin	0.1%					
Analgesics	1.0%					
Sedatives, Hypnotics, and Anxiolytics	0.3%	0.2%	0.4%	0.2%	0.3%	0.29%
Stimulants						
Amphetamine	0.2%	0.3%	0.1%	0.2%	0.2%	0.2%
Cocaine	0.2%	0.4%	0.1%	0.3%	0.4%	0.1%
Nicotine Dependence				13%	14%	12%

Source: APA, 2013.

Table 2 outlines substance use trends among youth.

Table 2
Substance Use Among Youth Ages 12 to 17

Substance	Past Month Use
Alcohol	9.6%
Cigarettes	4.2%
Smokeless tobacco	1.5%
Heroin	0.1%
Sedatives	0.1%
Tranquillizers	0.7%
Stimulants	0.5%
Marijuana	7.0%
Prescription pain relievers	1.1%
Psychotherapeutic drugs	2.0%
Inhalants	0.7%
Methamphetamine	0.1%
Cocaine	0.2%
Hallucinogens	0.5*%

Source: Center for Behavioral Health Statistics and Quality, 2016

\*In 2015, the National Survey on Drug Use and Health (NSDUH) estimate of any hallucinogen use was expanded to include the use of ketamine, DMT/AMT/Foxy, and salvia divinorum.

Another study that includes substance use prevalence in Virginia provides additional insight. Table 3 outlines prevalence rates in Virginia.

Table 3

Youth Substance Use in Virginia Ages 12 to 17

Substance	Past Month Use	Past Year Use
Illicit drugs	7.4%	
Cigarettes	5.0%	
Binge alcohol use among individuals 12-20	13.4%	
Nonmedical use of prescription pain relievers		4.8%

Source: SAMHSA, Behavioral Health Barometer Virginia, 2015.

These findings are alarming because substance use among youth has been associated with a number of negative consequences, including physical aggression, academic and occupational problems, delinquency and criminal behavior, developmental problems, and long-term health problems (U.S. Department of Health and Human Services, 2007). In addition, children and adolescents who become chronic substance users often develop psychological or social

problems. There is evidence that supports the relationship between substance abuse and criminal behaviors in youth. Juvenile offenders demonstrate elevated rates of substance abuse in comparison to non-offending youth. Substance abuse often increases recidivism and reflects a deeper involvement in the juvenile justice system (Carter, 2012). Drug and alcohol use also increases the likelihood that a youthful offender will have prolonged interaction with the juvenile justice system. Severe substance abuse is associated with increased rates of offending and more serious offenses. Furthermore, in general, the younger the child is at the onset of substance use, the greater the probability of severe and chronic offending (Carter).

#### **Causes and Risk Factors**

There are a number of factors that place youth at a higher risk for initiating and continuing substance use. A combination of physiological and environmental factors influences risk for addiction (National Institute on Drug Abuse, 2016). In addition, adolescent substance use itself is a known risk factor for the development of later alcohol and substance use problems, as well as related externalizing disorders such as antisocial personality disorder (Meyers & Dick). Understanding the early risk factors and trajectories that make these youths vulnerable to substance use disorders is crucial to the development of effective strategies for prevention.

# **Biological Process of Addiction**

Addiction is a brain disease that develops over time. Long-term substance use causes profound changes in brain structure and function, which result in uncontrollable, compulsive drug or alcohol craving, seeking, and substance using (Leshner, 2001).

According to Harvard Medical School (2011), addiction occurs when substances of abuse hijack the reward center of the brain. The brain is designed to encourage life-sustaining and healthy activities through the release of the chemical dopamine. Substances of abuse flood the brain's dopamine circuits with much more dopamine than natural rewards generate (addictive drugs can release two to 10 times the amount of dopamine as do natural rewards). This causes feelings of intense pleasure. However, the presence of excess dopamine causes the brain to adapt by producing and absorbing less dopamine. This process is called "tolerance." As an individual develops tolerance to a drug, he or she must take more of it to obtain the same "high." The pleasure associated with the drug eventually subsides, but because dopamine is also involved in learning and memory, the memory of that pleasure remains extremely salient, causing intense craving. Eventually, the addicted individual becomes biologically and psychologically compelled to take the drug.

# Physiological Risk Factors

Several physiological factors can make it more likely that an individual will become addicted to a substance. The later stages of puberty, regardless of chronological age, is in itself a risk factor, and adolescents entering puberty at an earlier age also enter the risk period earlier (Patton et al., 2005). Young people entering puberty who also have sensation-seeking traits may have an increased likelihood of substance use, while youth who exhibit impulse control seem to have a reduced likelihood of substance use (Castellanos-Ryan et al., 2013).

Having a mental health disorder also places youth at a higher risk for developing a substance use disorder (Bukstein, 1998; Conway, 2016). The presence of a childhood conduct disorder is a major risk factor for substance abuse (Brook et al., as cited by Kamon, Budney, & Stanger, 2005; Meyers & Dick, 2010). Substance abuse and conduct problems share risk factors, including family conflict, poor parental monitoring, parental substance use, academic problems, and association with delinquent peers (Anderson et al., as cited by Kamon, Budney, & Stanger). More than half of adolescents with substance abuse problems also experience conduct problems, which can make treatment of substance abuse particularly challenging (Kaminer et al., as cited by Kamon, Budney, & Stanger). Genetic influences can also be risk factors for substance abuse. Although there is no single gene that makes an individual more susceptible to substance abuse, there are multiple genes of subtle effects that interact to make the individual more vulnerable to a host of behaviors and disorders. These genetic vulnerabilities work in tandem with the individual's dynamic environment to become risk factors (NIDA, 2014).

Twin methodology has been used to study the contribution of genetic and environmental influences on a particular trait or disease state. Twin studies provide an estimation of a trait's heritability in a population. Heritability of substance use disorders varies among substances (and the measure of substance use), populations, age, and sex (Meyers & Dick, 2010). A 2006 meta-analysis of twin studies showed that the heritability of all addictive substances ranges from 40 to 60 percent (Goldman, Oroszi, & Ducci, as cited by Meyers & Dick). Heritability in the range of 30 to 60 percent are also observed for illicit drug use.

A study utilizing the Virginia Twin Registry sample to identify common genetic factors underlying the major class of psychiatric and substance use disorders found that a common genetic factor was shared across alcohol dependence, illicit drug dependence, adult antisocial behavior, and childhood conduct disorder (Kendler et al., as cited by Meyers & Dick). Several other studies have found that a common genetic factor, broadly termed the externalizing factor, accounts for the significant portion of the variance in alcohol dependence, abuse/dependence on other drugs, adult antisocial behavior, and childhood conduct disorder (Meyers & Dick, 2010).

Studies have also linked cAMP response element-binding protein (CREB) in the process of substance tolerance, dependence, and withdrawal symptoms (Davis, 2004). Various immunoblotting data have shown that CREB protein or activated CREB is regulated by various drugs of abuse within brain regions implicated in addiction (Ekanem, Sunday, & Gaim, 2016). The precise role of CREB in mediating addiction-related behaviors is still unclear.

#### **Environmental Factors**

Buu (2009) examined the long-term effects of family and neighborhood risk factors on adolescent substance use. The study found that parental substance use disorders, family socioeconomic status, family mobility, neighborhood residential instability, and neighborhood environmental change placed adolescents at risk for developing substance use disorders. Adolescents with a history of physical and/or sexual abuse were also more likely to be diagnosed with substance use disorders (Shane et al., as cited by NIDA, 2014). Many other risk factors, including prenatal exposure to alcohol or other drugs, lack of parental supervision or monitoring, and association with drug-using peers also play an important role (Nash, McQueen, & Bray, as citied by NIDA).

One study found that youth exposed to traumatic events had a greater likelihood of using substances (Carliner et al., 2016). Exposure to any traumatic event before age 11 years was reported by 36 percent of the study participants and was associated with higher risk for use of marijuana, cocaine, prescription drugs, other drugs, and multiple drugs (Carliner et al.). A significant finding was that exposure to interpersonal violence was associated with all drug use outcomes. Traumatic accidents were associated with higher risk for marijuana, cocaine, and prescription drug use. The researchers concluded that traumatic events in childhood are associated with risk for illicit drug use among U.S. adolescents. The results also highlight that adolescents with a trauma history are a high-risk group for illicit drug use and may benefit from trauma-focused prevention efforts that specifically address traumatic memories and coping strategies for dealing with stressful life events.

It is important to note that environmental and social risk factors may differ significantly during different phases of the youth's development. Parental and peer influences are often critical in early phases of substance use, while the influence of peers may increase as the child gets older (SAMHSA, 1999). In addition, a youth's vulnerability to these influences also influences their risk of using substances. Studies have found that a child's or adolescent's level of susceptibility or vulnerability to risk factors (in other words, their level of sensitivity to their environments) influences the likelihood of developing a substance use disorder (Leshner, 2001; McGue, & Iacono, 2008).

# Comorbidity

Existing regional and community studies have shown that the majority of youth with substance use disorders have a comorbid conduct disorder (CD), oppositional defiant disorder (ODD), or depression, and also that prior psychiatric conditions during adolescence may predict substance use disorders later in life (Conway et al., 2016). Another study showed that childhood ADHD, ODD, CD, and depression increase the risk of developing substance use disorders (Groenman et al., 2017).

An investigation by Conway et al. (2016) found that over 37 percent of adolescents experienced at least one mental health disorder before their first use of alcohol, over 47 percent before regular alcohol use, and over 66 percent before alcohol abuse. For drug categories, over 41 percent of adolescents met criteria for at least one mental disorder before having the opportunity to use drugs, over 53 percent before first drug use, and over 66 percent before drug abuse. Regarding specific mental disorders, higher rates across the stages of alcohol and illicit drug use were typically observed for adolescents with anxiety or behavior disorders, whereas the lowest rates were observed for individuals with phobia or eating disorders. In particular, the rates of alcohol abuse were much higher among adolescents with prior anxiety disorders (17.3 percent) and behavior disorders (15.6 percent) than their counterparts with prior phobia disorders (8.5 percent) or eating disorders (9.7 percent). Nearly one-fourth of adolescents with a prior behavior disorder and one-fifth of adolescents with an anxiety disorder developed illicit drug abuse. The findings confirm that the burden of substance use disorders in adolescence is disproportionately concentrated among youth with prior mental disorders, and that this burden is not limited to treated samples. The risk posed by prior mental disorders also varied considerably by stages of substance use.

A separate analysis found that comorbidity with ADHD, mood, or anxiety disorders is very common among U.S. adolescents who have substance use disorders (Zorick, 2012). Again, these data reinforce and extend many previous studies conducted in regional sample populations, demonstrating that substance use disorders among adolescents are highly comorbid with behavioral, mood, and anxiety disorders. A representative sample of 4,000 adolescents found that comorbid psychiatric conditions were associated with worse psychosocial functioning then those diagnosed with only a substance use disorder. Increased severity of addiction was also associated with an increased risk of psychiatric comorbidity (Zorick). These study findings show that adolescent behavioral disorders tend to be highly associated with the propensity to develop substance use disorders (Zorick).

Finally, epidemiologic studies find that it is not uncommon for individuals to abuse more than one substance. Instead, polysubstance abuse/dependence is the norm, with high rates of comorbidity across various drug classes (Meyers & Dick, 2010). Specific to cannabis use, comorbidity can include use of additional drugs, including opioids and cocaine. Along with co-occurring drug use, psychological conditions include depression, anxiety, suicide, and conduct disorder, along with decreased life satisfaction and increased mental health treatment and hospitalization (APA, 2013). Adolescents who use hallucinogens, including ecstasy, are more likely to have other substance use disorders and antisocial personality disorder (APA).

# **Screening and Assessment**

The following is taken from Yaghmaie and Weinstock (2012). The goal of comprehensive clinical assessment of adolescent addiction is to accurately identify signs and symptoms of problematic substance use so that prevention and early intervention can take place. Unlike screening, clinical assessment is a more comprehensive process in which the diagnosis of substance use disorders and other comorbid psychiatric conditions is established via clinical interview and focused physical examination. If consent is provided, additional information can be obtained from lab testing, past medical records, other clinicians, and from parents or other people who know the adolescent. Several structured and semi-structured interviews for evaluation of substance abuse are available that can identify substance abuse problems with greater validity than a non-structured clinical assessment. However, structured interviews can sometimes misinterpret special situations and miss important details better identified in comprehensive clinical interviews. It is important to supplement structured interviews with more in-depth clinical inquiries and interviewing. A comprehensive evaluation of adolescent substance use should cover a variety of elements. These are outlined in Figure 1.

When assessing youth suspected of co-occurring disorders, the primary goal is to determine whether substance use also exists and whether it fits the established criteria for substance use disorders (Bukstein, 1998). If a clinician has concerns about substance abuse during screening, assessment for substance abuse should proceed (Bukstein, 2005). This can be assessed using diagnostic instruments such as the Kiddie-Schedule for Affective Disorders and Schizophrenia and Lifetime Version or the Diagnostic Interview Schedule for Children. This determination should also be based on a comprehensive developmental, social, and medical history. Evaluators should obtain the necessary information from a variety of sources, including the youth, parents, family members, school personnel, previous treatment records, and perhaps other involved agencies (SAMHSA, 1997; Bukstein, 2005). Additionally, toxicology testing should be a part of

ongoing assessment and treatment of substance use disorder in youth (Bukstein). Once clinicians have established that the youth is using substances, they must then determine the nature of the use pattern.

Figure 1

Domains to Assess When Evaluating for Addiction

History of substance abuse		Family history		
	History of problematic behavior	Home environment/peer relationships		
	Psychiatric history	Developmental issues, trauma/abuse history		
	Medical history	Academic and vocational history		
	Physical and mental status evaluation	Legal history		
	Sexual history	Motivation and capacity for change		

Source: Yaghmaie & Weinstock, 2012.

Recognition of co-occurring substance use and mental health disorders is often difficult, and clinicians should consider several issues when conducting the evaluation. The youth may display denial, distortion, and minimization when discussing substance use; therefore, the details provided by them may not be reliable. Furthermore, in cases of co-occurring mental health disorders, the youth and family may not fully understand the reasons for the distressing symptoms and behaviors. Therefore, the information provided during the evaluation may not be particularly revealing (Bukstein, 1998). Moreover, reports of substance use may be distorted by the cognitive and emotional aspects of any underlying mental health disorder, further decreasing the validity of self-reporting (Mueser, Drake, & Miles, 1997).

Clinicians must also consider that youth with co-occurring mental health and substance use disorders often present different symptoms than substance abusers who do not have a mental health disorder (Mueser, Drake, & Miles, 1997). They may use lower amounts of alcohol and/or drugs and experience different consequences from use. Based on these differences, standard instruments may not identify the substance use disorder in these youth and the clinician may have to rely primarily on clinical interviews and patient histories.

There are a number of screening and assessment tools specifically designed to measure diagnostic criteria for substance use disorders, the nature of substance use, and impairment in functioning among adolescents:

Adolescent Diagnostic Interview (ADI; Winters & Henly, 1993) is a structured interview that assesses *DSM-IV* criteria for substance use disorders and measures the adolescent's level of functioning across several domains (e.g. peers, school behavior, and home behavior). The test-retest and interrater reliability is well-established for this instrument (Winters, 1999).

Adolescent Drug Abuse Diagnosis (ADAD; Friedman & Utada, 1989) instrument is a structured comprehensive interview that assesses substance use and nine life problems and

can be used for both treatment planning and assessing behavioral change over time. ADAD is reliable among raters and test-retest processes, and its external validity is adequate for most of the nine life problems scales (Winters, 1999).

Adolescent Self-Assessment Profile (ASAP; Wanberg, 1992) is a self-report instrument that provides a differential assessment for an adolescent's substance use and psychosocial adjustment. It can be used in treatment to assess behavior and adjustment changes across time, and it has excellent reliabilities and good content and construct validity (Winters, 1999).

American Drug and Alcohol Survey (ADAS; Oetting, Beauvais, & Edwards, 1985) is a self-report instrument that assesses levels of substance use. This instrument can assess the magnitude of substance use among youth and is most useful at the local level.

<u>Chemical Dependency Assessment Profile</u> (CDAP; Harrell, Honaker, & Davis, 1991) is a multiple-choice and true-false self-report measure. It assesses history of chemical use, patterns of use, reinforcement mechanisms, perception of situational stressors, and attitudes related to treatment, self-concept, and interpersonal relations. Psychometric properties for this measure could not be found (Winters, 1999).

The Center for Adolescent Substance Abuse Research Screening Tool (CRAFFT; Center for Adolescent Substance Abuse Research, 2016) is a six-question behavioral health screening tool to screen adolescents for high risk alcohol and other drug use disorders simultaneously. It has been recommended by the American Academy of Pediatrics' Committee on Substance Abuse for use with adolescents under the age of 21.

<u>Juvenile Automated Substance Abuse Evaluation</u> (JASAE; ADE, Inc., 1987) is a computer-assisted screening and assessment instrument that assesses substance use and abuse among juveniles, as well as attitude and life stressors. It is a brief assessment and is often used in conjunction with more extensive interviews (Miller, 1999; Winters, 1999).

<u>Personal Experience Inventory</u> (PEI; Winters & Henly, 1989) is a comprehensive assessment that assesses substance use and related problems, problem severity, and psychosocial risk factors. The scales have been found to be reliable and valid for assessing substance use disorders in African American, Latino, Asian American, and Native American populations (Winters, 1999).

Table 4 lists the assessment tools that may be used for substance use disorder.

Table 4
Suggested Screening and Assessment Tools for Substance Use Disorder

Name of Measure	Measure Type	Who Completes	Generated Information
Kiddie-Schedule for Affective Disorders (K-SADS) and Schizophrenia and Lifetime Version	Clinical interview	Clinician with youth and parent	Diagnosis
Diagnostic Interview Schedule (DISC)	Clinical interview	Clinician with youth and parent	Diagnosis
Adolescent Diagnostic Interview (ADI)	Clinical interview	Youth	Diagnosis
Adolescent Drug Abuse Diagnosis (ADAD)	Clinical interview	Youth	Symptom ratings
Adolescent Self-Assessment Profile (ASAP)	Self-rating scale	Youth	Symptom ratings
American Drug and Alcohol Survey (ADAS)	Self-rating scale	Youth	Symptom ratings
Chemical Dependency Assessment Profile (CDAP)	Self-rating scale	Youth	Symptom ratings
The Center for Adolescent Substance Abuse Research Screening Tool (CRAFFT)	Self-rating scale	Clinician with youth and parent	Initial screen to determine if risky behaviors are present
Juvenile Automated Substance Abuse Evaluation (JASAE)	Self-rating scale	Youth	Symptom ratings
Personal Experience Inventory (PEI)	Self-rating scale	Youth	Symptom ratings

Sources: Commission on Youth Graphic of citations provided in text.

#### **Treatments**

Treatment for substance use disorders is delivered at varying levels of care in many different settings (NIDA, 2014). Because no single treatment is appropriate for every youth or adolescent, treatments must be tailored for the individual. Based on the consensus of drug treatment experts, the American Society of Addiction Medicine (ASAM) has developed guidelines for determining the appropriate intensity and length of treatment for adolescents with substance abuse problems, based on an assessment involving the following six areas:

- 1. Level of intoxication and potential for withdrawal
- 2. Presence of other medical conditions
- 3. Presence of other emotional, behavioral, or cognitive conditions
- 4. Readiness or motivation to change
- 5. Risk of relapse or continued drug use
- 6. Recovery environment (e.g., family, peers, school, legal system) (ASAM, as cited by NIDA)

With a substance use disorder, as with any other medical condition, treatment must be long enough and strong enough to be effective. Substance abuse treatment must continue for a sufficient length of time to treat the disease. Undertreating a substance use disorder—providing lower than the recommended level of care or a shorter length of treatment than recommended—will increase the risk of relapse and could cause the youth, their family members, or the referring system to lose hope in the treatment because they will see it as ineffective (NIDA, 2014).

The information in the following paragraphs is taken from NIDA (2014) and details the settings in which adolescent substance use treatment most often occurs.

Outpatient/Intensive Outpatient: Child and adolescent substance abuse treatment is most commonly offered in outpatient settings. When delivered by well-trained clinicians, this can be highly effective. Outpatient treatment is traditionally recommended for adolescents with less severe addictions, few additional mental health problems, and a supportive living environment, although evidence suggests that more severe cases can be treated in outpatient settings as well. Outpatient treatment varies in the type and intensity of services offered and may be delivered on an individual basis or in a group format. Low- or moderate-intensity outpatient care is generally delivered once or twice a week. Intensive outpatient services are delivered more frequently, typically more than twice a week for at least three hours per day. Outpatient programs may offer substance use prevention programming focused on deterring further drug use or other behavioral and family interventions.

<u>Partial Hospitalization</u>: Youth with more severe substance use disorders but who can still be safely managed in their home living environment may be referred to a higher level of care called partial hospitalization or "day treatment." This setting offers adolescents the opportunity to participate in treatment four to six hours a day at least five days a week while living at home.

Residential/Inpatient Treatment: Residential treatment is a resource-intense high level of care, generally for youth and adolescents with severe levels of addiction whose mental health and medical needs and addictive behaviors require a 24-hour structured environment to make recovery possible. These adolescents may have complex psychiatric or medical problems or family issues that interfere with their ability to avoid substance use. One well-known long-term residential treatment model is the therapeutic community (TC). TCs use a combination of techniques to "resocialize" the adolescent and enlist all the members of the community, including residents and staff, as active participants in treatment. Treatment focuses on building personal and social responsibility and developing new coping skills. Such programs offer a range of family services and may require family participation if the TC is sufficiently close to where the family lives. Short-term residential programs also exist.

Once the treatment setting has been determined, numerous methods are used to treat children and adolescents with substance use disorders. These treatments are discussed in the following paragraphs and are outlined in Table 5.

Table 5
Summary of Treatments for Substance Use Disorder

What Works						
Cognitive behavioral therapy (CBT)	A structured therapeutic approach that involves teaching youth about the thought-behavior link and working with them to modify their thinking patterns in a way that will lead to more adaptive behavior in challenging situations.					
Family therapy Multidimensional family therapy (MDFT) Functional family therapy (FFT)	Family-based therapy is aimed at providing education, improving communication and functioning among family members, and reestablishing parental influence through parent management training. MDFT views drug use in terms of networks of influences (individual, family, peer, community) and encourages treatment across settings in multiple ways. FFT is best used in youth with conduct and delinquent behaviors along with substance use disorders combining relationship with CBT interventions to change relationship patterns and improve the family's functioning.					
Multisystemic therapy (MST)	An integrative, family-based treatment with a focus on improving psychosocial functioning for youth and families.					
What Seems to Work	What Seems to Work					
Behavioral therapies	Behavioral therapies focus on identifying specific problems and areas of deficit and working on improving these behaviors.					
Motivational interviewing (MI)  Motivational enhancement therapy (MET)	MI is a brief treatment approach aimed at increasing motivation for behavior change. It is focused on expressing empathy, avoiding argumentation, rolling with resistance, and supporting self-efficacy. MET is an adaptation of MI that includes one or more client feedback sessions in which normative feedback is presented and discussed.					
Pharmacological treatments	Some medication can be used for detoxification purposes, as directed by a doctor. Medication may also be used to treat co-existing mental health disorders.  **Continued next page**					

Table 5 (continued)

Summary of Treatments for Substance Use Disorder

Not Adequately Tested	
Multifamily educational intervention (MEI)	MEI combines psycho-educational and family interventions for troubled adolescents and their families.
Adolescent group therapy (AGT)	The AGT intervention incorporates adolescent therapy groups on stress management, developing social skills, and building group social support.
Interpersonal and psychodynamic therapies	Interpersonal and psychodynamic therapies are methods of individual counseling that are often incorporated into the treatment plan and focus on unconscious psychological conflicts, distortions, and faulty learning.
Client-centered therapies	A type of therapy focused on creating a non-judgmental environment, such that the therapist provides empathy and unconditional positive regard. This facilitates change and solution making on behalf of the youth.
Psychoeducation  Programs aimed at educating youth on substance use and may cover topics peer pressure and consequences of substance use.	
Project CARE	A program aimed at raising awareness about chemical dependency among youth through education and training.
Twelve-step programs	A twelve-step program that uses the steps of Alcoholics Anonymous as principles for recovery and treating addictive behaviors.
Process groups  A type of psychotherapy that is conducted in a small group setting. be specialized for specific purposes and therapy utilizes the group a mechanism of change.	

# Psychological Treatments

Numerous psychological treatments are used to treat youth with substance use disorders. These are discussed below.

#### Cognitive Behavioral Therapy (CBT)

The goal of CBT is the identification and modification of maladaptive thinking patterns to reduce negative thoughts, feelings, and behavior. For substance abusers, the focus of this intervention is generally relapse prevention (NIDA, 2014; Becker & Curry, 2008; Leukefeld et al., 2015). CBT can help the adolescent develop greater self-control; identify environmental and internal triggers leading to relapse; and develop strategies for dealing with stressors, triggers, and lapses into substance use. The role of clinicians is to aid the youth in anticipating the problems that they are likely to meet and to help them to develop effective coping strategies. The two main elements of CBT are functional analysis, identifying the thoughts and feelings before and after substance use, and skills building, such as ways to overcome peer pressure and increase pleasant activities (Effective Child Therapy, 2012). CBT also addresses social skills, anger control, and problem-solving (Bukstein, 2005; American Psychological Association [APA] Division 53, 2012).

Several research studies support CBT as effective in treating a wide range of substance use disorders (Miller & Wilbourne, 2002; Stephens, Roffman & Curtin, 2000; Waldron et al., 2001). Studies have also indicated that CBT also has positive effects with adolescents treated for mental health disorders such as depression (Bukstein, 1998). In addition, studies have shown that CBT is effective for adolescents diagnosed with conduct disorder and co-occurring substance abuse disorders (Kazdin, as cited by Bukstein, 2005).

#### Family Therapy

Although family therapy is considered an important modality in the treatment of adolescents with substance use disorders (Bukstein, 1998), clinicians and consumers should be aware that family therapy is a very broad term that encompasses a large number of treatment programs. Not all of these family therapies have been tested with children and adolescents with substance use disorder. Thus, it is important and relevant to ask "what kind of family therapy" when family therapy is recommended. Common elements across most family therapies include:

- Engaging the family (versus working with the child alone);
- Focusing on education about substance use and abuse;
- Emphasizing communication skills to improve family functioning; and
- Reestablishing parental influence through parent management training (Bukstein, 1998).

Though family therapy is important, it may be contraindicated if family members actively abuse substances, are violent, deny that the youth's substance use is problematic, or remain unreasonably angry (SAMHSA, 2012).

One program with empirical support is Multidimensional Family Therapy (MDFT), an outpatient, family-based treatment for adolescents with serious substance abuse issues (Liddle, 2009; APA Division 53, 2012; Leukefeld et al., 2015). This approach views drug use in terms of a network of influences (individual, family, peer, community) and encourages treatment across settings in multiple ways. Sessions may be held in a clinic, home, court, school, or other community locations. For the child or adolescent, the emphasis of treatment is on skill-building, and the treatment plan often incorporates practicing developmental tasks such as decision-making, negotiation, problem-solving, performing vocational skills, communication, and dealing with stress (Liddle, 2009; APA Division 53). Parallel sessions are held with family members, in which parents examine their parenting style, learn to distinguish influence from control, and learn to have a positive and developmentally appropriate influence on their child. Research supports the use of this type of therapy for adolescents with substance use disorders (Leukefeld et al.; NIDA, 2014).

Another well-established therapy method is Functional Family Therapy (FFT). FFT is best used in youth with conduct and delinquent behaviors along with substance abuse (APA Division 53, 2012). This short-term process combines relationship with CBT interventions to change relationship patterns and improve the family's functioning (APA Division 53). FFT is specifically designed for youth ages 12 to 18, and is successful across locations and ethnic groups (APA Division 53). The effects of FFT endure years after treatment, at times into adulthood, and can positively impact siblings of affected youth as well (APA Division 53).

A method of strategic family therapy has also been tested and found effective with substance using adolescents. Szapocznik et al. (1989) tested their strategic model against usual methods. The model included educational information for the parents and youth, communication skills training, and cultural training to integrate a family's cultural practices into treatment. Brief Strategic Family Therapy (BSFT) attempts to reduce negative behaviors, promote positive behaviors such as school attendance and performance, and improve family functioning. Clinicians typically administer 12 to 16 family sessions in convenient locations, at times even in the family home (APA Division 53, 2012).

# Multisystemic Therapy (MST)

One promising intervention program for youth with co-occurring substance use and mental health disorders is MST. MST aims to address the multifaceted nature of antisocial behavior at the individual, family, and community levels (Ouimette, 2007). This form of therapy is intended to address serious antisocial behavior in children and adolescents who abuse substances. Therapeutic efforts target the child's behavior within the context of the family environment, the school environment, and the neighborhood and community (NIDA, 2012; APA Division 53, 2012). MST helps develop a support network of extended family, neighbors, and friends to help caregivers achieve and maintain such changes (APA Division 53). Treatment occurs in each of the child's natural settings. Research has shown that MST significantly reduces adolescent drug use during treatment and for at least six months after treatment (NIDA, 2014). It has also been found to reduce the number of juvenile incarcerations and out-of-home placements (NIDA, 2012).

MST is associated with significant, long-term reduction of aggressive behaviors in chronic and violent juvenile offenders (Henggeler & Brondino, 2002). Several research studies have reported that MST is associated with decreases in arrest and substance use rates (Borduin et al., 1990; Borduin et al., 1995). Clinical trials indicate that MST is an effective intervention for substance-abusing youth, particularly for marijuana abstinence (Henggeler & Brondino).

#### **Behavioral Therapies**

The core of behavioral therapy is that behavior is learned and can be unlearned (University of North Carolina Greensboro [UNCG] Center for Youth, Family, and Community Partnerships, 2008). Behavioral therapies with research support include goal monitoring, contingency management, and skill-building approaches. The underlying goal of a goal monitoring approach is to allow the youth and the treatment provider to identify specific problems and areas of deficit and to work on improving these behaviors (Bukstein, 1998). Therapeutic activities are then designed to achieve these goals and may include fulfilling specific assignments, rehearsing desired behaviors, and recording and reviewing progress (NIDA, 2012). Contingency management (CM) interventions are sometimes used separately or in conjunction with a goal monitoring approach. In CM approaches, positive reinforcers are provided at intervals based on specific behaviors from the youth. Both goal monitoring and CM approaches are often incorporated into inpatient, residential, or partial hospitalization programs (Bukstein).

In community-based care, caregivers are taught to monitor goals and/or more effectively manage contingencies. Research shows that, when consistently applied, this type of therapy helps

adolescents become drug-free and increases their ability to maintain abstinence after treatment ends (Azrin et al., 1996; NIDA, 2014). Participants have also been found to show improvement in areas such as employment, school attendance, family relationships, depression, and institutionalization (NIDA).

# Motivational Enhancement Therapy (MET) and Motivational Interviewing (MI)

MI is a directive, client-centered counseling style for eliciting behavior change by helping clients to explore and resolve their ambivalence and achieve lasting changes for a range of problematic behaviors. This intervention has been extensively tested in treatment evaluations of alcohol and other drug use/misuse. MI is a brief treatment approach that aims to increase motivation for behavior change in addicted and related problematic behaviors. It is based on five core principles, including the expression of empathy, highlighting discrepancies, avoiding argumentation, rolling with resistance, and supporting self-efficacy (Evans et al., 2005). Motivational approaches are accepting of ambivalence and uncertain motivation, and work on exploring these ambivalences. There has been ample support for the efficacy of MI in treating substance use disorders among adults (Burke, Arkowitz, & Menchola, 2003).

MET is an adaptation of MI that includes one or more client feedback sessions in which normative feedback is presented and discussed in an explicitly non-confrontational manner (Improving Practices, 2017). Research examining MET and MI among youth has found support for the efficacy of motivational interviewing in reducing substance related behaviors (Improving Practices; Leukefeld et al., 2015; Monti et al., 1999).

# Pharmacological Treatments

The target areas for the use of pharmacotherapy among adolescents with substance use disorders include treating withdrawal symptoms or substituting a legal drug for an illicit substance during prolonged withdrawal or maintenance, counteracting the physiological and subjective effects of abused substances, and treating comorbid psychiatric disorders (Bukstein, 1998). Clinicians should, however, use caution in considering pharmacological treatment for adolescents with comorbid substance use disorders and psychiatric disorders. The presence of substance use may increase the potential for intentional or unintentional overdose with some medications, especially in combination with some substances of abuse (Bukstein, 2005). When medication is utilized for the treatment of a co-occurring mental health disorder, a cautious approach, as well as an integrated treatment strategy, is crucial (J. Aaron, personal communication, October 17, 2017).

Accordingly, NIDA recommends that medication should be pursued only as a last resort in this population due to the potential for misuse and overdose (2014). This is particularly relevant for drugs that are likely to be abused (J. Aaron, personal communication, October 17, 2017). Furthermore, medications should be prescribed only to those children and adolescents who displayed psychiatric symptoms prior to the substance use or only if the symptoms are present during periods of abstinence (NIDA). A definitive assessment requires that the youth abstain from the use of substances for a specified period, typically several weeks. Finally, if medication is prescribed, it is critical that the youth's physician closely monitors the medication regimen with the awareness that the youth may still be using other illicit substances.

Several medications have been found to be effective in treating addiction to opioids, alcohol, and nicotine in adults, although none of these medications have been approved by the FDA to treat adolescents (NIDA, 2014). In most cases, only preliminary evidence exists for the effectiveness and safety of these medications in people under 18, and there is no evidence on the neurobiological impact of these medications on the developing brain. However, despite the relative lack of evidence, some health care providers do use medications when treating adolescents (especially older adolescents) who are addicted to opioids, nicotine, or alcohol. Newer compounds continue to be studied for possibly treating substance use disorders in adults and adolescents. Note that there are currently no FDA-approved medications to treat addiction to cannabis, cocaine, or methamphetamine in any age group (NIDA).

According to the American Society of Addiction Medicine (ASAM), clinicians should consider treating adolescents who have opioid use disorder using the full range of treatment options, including pharmacotherapy (ASAM, 2015). Opioid agonists (methadone and buprenorphine) and antagonists (naltrexone) may be considered for treatment of opioid use disorder in adolescents (ASAM). Age is a consideration in treatment, and federal laws and FDA approvals need to be considered for patients under age 18. More research is needed to identify which psychosocial treatments, alone and in combination with pharmacotherapy, are best suited for use with adolescents.

# **Unproven Treatments**

Two peer-led interventions—Multifamily Educational Intervention (MEI) and Adolescent Group Therapy (AGT)—were tested against the efficacy of MDFT treatment intervention described previously (Leukefeld et al., 2015). MEI combined psycho-educational and family interventions for troubled adolescents and their families. AGT incorporated adolescent therapy groups on stress management, developing social skills, and building group social support. Although each of the adolescents in these three treatment approaches demonstrated some improvement, the adolescents in the AGT and MEI treatments had higher drop-out rates, higher substance use, lower academic performance, and showed less family functioning compared to MDFT. Given the efficacy of MDFT and the more limited success of AGT compared to MEI, a critical aspect of successful treatment is the concurrent focus on the adolescent and his/her family in individualized-tailored treatment (Leukefeld et al.).

The following information is from the 2007 Biennial Report of the Hawaii Department of Health (Chorpita & Daleiden, 2007). For the treatment of substance abuse, studies have found no support for the following treatments: client-centered therapy, education, group therapy, Project CARE, or 12-step programs. Moreover, these findings also indicate that group therapy and Project CARE treatment approaches may negatively affect treatment outcomes for substance abuse. However, some group therapy approaches may be appropriate, as described here, while others may be counterproductive.

According to NIDA, many youth have poor compliance in participating in aftercare interventions and resist involvement in 12-step programs and other post-treatment recovery activities (2015). Adolescents do not wish to be stigmatized as having a disease or being in recovery. They also may not view their addiction as a disease. As a result, up to 85 percent of adolescents relapse within one year of receiving treatment. An interactive mobile texting aftercare program has

shown promise as a means to help youth and adolescents engage in post-treatment recovery activities and avoid relapse. In a pilot study, one program called Educating & Supporting Inquisitive Youth in Recovery (ESQYIR), reduced young people's odds of relapsing by half compared with standard aftercare (NIDA). Additional research is needed to learn more about the effectiveness of this intervention.

#### **Cultural Considerations**

Research indicates that there may be ethnic differences in risk factor profiles and that cultural differences should be taken into account when considering how risk factors predict substance use problems (Vega et al., 1993). The *DSM-5* specifies marked differences in prevalence rates across racial and ethnic subdivisions. These differences are outlined in Table 6.

Table 6

Twelve Month Substance Abuse Prevalence Across
Race/Ethnic Subgroups in US Population

Substance	Age Group*	Hispanics	Native Americans & Alaska Natives	Caucasians	African Americans	Asian Americans & Pacific Islanders
A11-1	Youth	6.0%	5.7%	5.0%	1.8%	1.6%
Alcohol	Adults	7.9%	12.1%	8.9%	6.9%	4.5%
G I	Youth	4.1%	7.1%	3.4%	2.7%	0.9%
Cannabis	Adults	1.2%	3.4%	1.4%	1.8%	1.2%
	Youth	0.6%	1.2%	0.6%	0.2%	0.2%
Hallucinogens	Adults	0.2%	0.2%	0.2%	0.03%	0.07%
Sedatives,	Youth	0.2%	0.1%	0.3%	0.2%	0.1%
Hypnotics, or Anxiolytics	Adults	0.2%	0.8%	0.2%	0.2%	0.1%
Stimulants						
Amphetamine	Youth	0.1%	0.0%	0.3%	0.3%	0.01%
	Adults	0.2%	0.6%	0.2%	0.0%	0.0%
Cocaine	Youth	0.2%	0.0%	0.2%	0.2%	0.2%
	Adults	0.3%	0.8%	0.2%	0.4%	0.1%
Nicotine Dependence	Adults	6%	23%	14%	10%	6%

\*Youth=12-17 years of age; Adults=18 years of age and older

Source: APA, 2013.

In addition, research cited by Walton (2001) suggests that females may enter substance abuse treatment with unique needs. Females present symptoms of greater psychological distress, such as low self-esteem and depression, and are much more likely to report prior physical and/or sexual abuse than their male counterparts. These issues must be effectively addressed within the context of treatment in order to improve outcomes.

Walton (2001) also cites research that has found that females and minorities often enter treatment with fewer financial resources and positive social supports. Studies have found that many African Americans are at a higher risk of relapse because they may face more difficult social situations following treatment, such as high-stress and low-support environments.

#### **Overview for Families**

Adolescents often have a hard time seeing the consequences of their actions. They frequently lack the ability to consider the lifelong physical, psychological, and social effects of substance abuse, which can lead to experimentation with drugs and alcohol. Alcohol, tobacco, and drug use have negative health effects (American Academy of Child & Adolescent Psychiatry AACAP, 2013). Substance use is associated with a variety of negative consequences including poor judgment, school failure, and alterations in brain structure, function, and neurocognition (AACAP, 2013; Squeglia, 2009).

Families should be aware of potential warning signs of drug use in adolescents. The first changes families often notice are in behavior and mannerisms (Ali et al., 2011). However, there are many warning signs, some of which include:

- Fatigue
- Red and glazed eyes
- Lasting cough
- Sudden mood changes
- Irresponsible behavior
- Poor judgment
- Depression
- Breaking rules and withdrawing from the family
- Negative attitude
- Drop in grades
- New friends that are less interested in standard home and school activities
- General discipline problems (AACAP, 2013)

Parents should talk to their children about drugs, be on the lookout for warning signs, and be good role models (AACAP). These conversations should take place at an early age and include discussions of alcohol and tobacco.

Some adolescents experiment with substance use, or use substances occasionally, without significant problems, while others become dependent. These youth often move to more dangerous drugs and can cause significant harm to themselves and others (AACAP, 2013).

While nobody knows which youth will develop serious substance use problems, certain adolescents are at higher risk for developing substance use disorder. These youth include those:

- With a family history of substance use disorders;
- Who are depressed or anxious;
- Who have low self-esteem; and/or
- Who feel like they don't fit in or are out of the mainstream (AACAP, 2013).

Figure 2 outlines additional risk factors, including those associated with the individual and the family. While none of these factors guarantee an adolescent will develop substance use disorder, families should be cognizant of the potential risks.

#### Figure 2

# Risk Factors for Substance Use Disorder in Adolescents and Teens

#### Family Risk Factors:

- Inadequate supervision from the family
- Inconsistent or severe discipline from the family
- Poor communication
- Family tension and conflicts
- Broken homes
- Family history of parental alcohol or drug abuse

#### Individual Risk Factors:

- History of early childhood negative and aggressive behavior or physical or sexual abuse
- Being an older adolescent Caucasian male
- Emotional, social, or academic problems
- Poor impulse control or thrill-seeking behaviors
- Emotional instability
- Very low perception of the dangers inherent in drug use

#### Other Risk Factors:

- Low socioeconomic status
- Level of education
- Living in a high crime and drug-use neighborhood
- Ease of drug availability
- Peer-group pressure
- History of mental illness

Source: Ali et al., 2011.

There are a variety of illegal drugs and legal substances that youth utilize. Legally available drugs include alcohol, prescribed medications, inhalants (fumes from glues, aerosols, and solvents), and over-the-counter cough, cold, sleep, and diet medications. The most commonly

used illegal drugs are marijuana (pot), stimulants (such as cocaine, crack, meth, and speed), LSD, PCP, opiates, heroin, and designer drugs (such as MDMA, also called ecstasy or molly) (AACAP, 2013).

Illegal drug use is growing, especially among young teens; first marijuana use is typically at the age of 14, and drinking alcohol can start before age 12 (AACAP, 2013). A variety of negative consequences result from substance use, including an increased risk of serious drug use later in life, school failure, and poor judgment, which puts teens at risk for accidents, violence, unplanned and unsafe sex, and suicide (AACAP). Families who talk to youth about drugs, have open communication, are positive role models, encourage responsible behavior, and recognize developing problems are most likely to curtail or prevent drug use (AACAP).

# **Resources and Organizations**

# **American Academy of Pediatrics Committee on Substance Abuse**

Substance Use Screening, Brief Intervention, and Referral to Treatment for Pediatricians http://pediatrics.aappublications.org/content/pediatrics/early/2011/10/26/peds.2011-1754.full.pdf

# Food and Drug Administration (FDA)

Risk Evaluation and Mitigation Strategy (REMS) (Extended-Release and Long-Acting Opioid Analgesics)

http://er-la-opioidrems.com/IwgUI/rems/home.action

#### Mental Health America (MHA) (formerly National Mental Health Association)

http://www.mentalhealthamerica.net/

#### **National Alliance for the Mentally III (NAMI)**

https://www.nami.org/

#### National Institute on Alcohol Abuse and Alcoholism (NIAAA)

https://www.niaaa.nih.gov/

#### **National Institute on Drug Abuse (NIDA)**

https://www.drugabuse.gov/

# Office of Juvenile Justice and Delinquency Prevention (OJJDP)

https://www.ojjdp.gov/

# **Stop Underage Drinking (Portal of Federal Resources)**

https://casaa.unm.edu/ctn/ctn%20mod%20tool%20kit/Prevention/Stop%20Underage%20Drinking%20%20Portal%20of%20Federal%20Resources.htm

# **Substance Abuse and Mental Health Services Administration (SAMHSA)**

https://www.samhsa.gov/

#### The GAINS Center for Behavioral Health and Justice Transformation

https://www.samhsa.gov/gains-center

# Virginia Department of Behavioral Health and Developmental Services (DBHDS)

http://www.dbhds.virginia.gov/

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# YOUTH SUICIDE

Introduction

Recent Changes from the DSM-IV to the DSM-5 Risk Factors Individual/Demographic Characteristics

Individual/Demographic Characteristics
Psychological Characteristics
Other Risk Factors

Assessment Interventions

Promising Practices in Youth Suicide Prevention
Not Adequately Tested
What Does Not Work
Overview for Families

#### Introduction

Youth suicide (i.e., self-inflicted injury resulting in death) and suicide attempts (i.e., self-inflicted injury with intent to die) constitute a major public health problem in the United States. Suicide is a leading cause of death for 10- to 24-year-olds (American Academy of Child and Adolescent Psychiatry [AACAP], 2013; Centers for Disease Control and Prevention [CDC], 2015). In 2013, for children ages five to 14, the most frequent causes of death were cancer (one per 100,000), suicide (one per 100,000), and birth defects (one per 100,000 children) (Federal Interagency Forum on Child and Family Statistics, 2015). However, for adolescents ages 15 to 19, almost three-fourths of their deaths were from injuries, with suicides accounting for 25 percent of these injury deaths. In ages 10 to 14, there has been a 128 percent increase in suicides since 1980 (The Jason Foundation, 2016). In Virginia, 49 children and adolescents between the ages five and 19 committed suicide in 2013 (Virginia Department of Health, Office of the Chief Medical Examiner, 2013). In fact, suicide ranked third for cause of death among 10- to 24-year-olds in Virginia (Virginia Performs, 2016).

Deaths from suicide are only part of the problem. More young people survive suicide attempts than die from them. Every two years, the CDC conducts a nationwide survey of youth in grades 9 through 12 in the United States. The Youth Risk Behavior Surveillance System (YRBSS) gathers information on priority health risk behaviors among youth, including five suicide-related behaviors: feeling sad or hopeless; seriously considering attempting suicide; making a suicide plan; attempting suicide; and making a suicide attempt that resulted in an injury, poisoning, or overdose that had to be treated by a doctor or nurse (CDC, 2014). In 2013, 17 percent of students reported seriously considering suicide, 13.6 percent reported creating a plan, and 8 percent reported trying to take their own life in the 12 months preceding the survey (CDC). In addition,

each year, approximately 157,000 youth between the ages of 10 and 24 receive medical care for self-inflicted injuries at emergency departments across the U.S. (CDC, 2015).

Nationwide, firearms are the most common method of suicide for youth, followed by suffocation and poisoning (CDC). Suicide methods also vary by age. Table 1 summarizes suicide methods by age in Virginia:

Table 1
Suicide Methods Within Age Groups in Virginia

Age Group —	Method of Suicide			
	Firearms	Hanging/Suffocation	Poison	
10 – 14 years old	34%	62.3%	3.8%	
15 – 19 years old	50%	38%	less than 10%	

Source: Jansson, 2016.

There has been increasing attention paid to the issues of suicide and suicide prevention. In 1999, the U.S. Surgeon General issued a "Call to Action" emphasizing the need for greater awareness of this national problem (U.S. Department of Health and Human Services [HHS], 2001). Shortly thereafter, HHS published *National Strategy for Suicide Prevention* to address issues such as collaboration with agencies and stakeholders (Vetter, 2002). In 2012, the Office of the U.S. Surgeon General and the National Action Alliance for Suicide Prevention issued a revised *National Strategy for Suicide Prevention*. The revised *Strategy* provides guidance for schools, businesses, health systems, clinicians, and many other sectors. It reflects advancements in the field since the last *Strategy* was published (HHS, Office of the Surgeon General and National Action Alliance for Suicide Prevention, 2012).

It is important to note that, although non-suicidal self-injury (NSSI) is very serious, the individual's intention and ambivalence about the outcome distinguish it from suicidal behavior (Miller, Rathus, & Linehan, 2007). A more detailed discussion of this disorder is included in the "Non-Suicidal Self-Injury" section of the *Collection*.

# Recent Changes from the DSM-IV to the DSM-5

In 2013, the American Psychiatric Association (APA) released the fifth edition of the *Diagnostic* and Statistical Manual of Mental Disorders (DSM-5). Suicidal behavior disorder was included as a condition for further study and proposed criteria were included to encourage future research (APA, 2013). The proposed criteria for this condition include the following:

- A suicide attempt within the past 24 hours;
- The act does not meet criteria for non-suicidal self-injury, thus it is not intended to relieve stress or to achieve a positive mood;
- The diagnosis is not applied to suicidal ideation or to preparatory acts;
- The act was not carried out during a state of delirium or confusion; and
- The act was not undertaken for a political or religious purpose (APA, 2013).

The *DSM-5* is a manual for assessment and diagnosis of mental health disorders and does not include information for treatment of any disorder. In the future, more evidence supporting treatments of disorders with *DSM-5* classifications will be available as clinical studies utilizing *DSM-5* criteria are conducted. As a result, this *Collection* will reference studies that utilize *Diagnostic and Statistical Manual, Fourth Edition (DSM-IV)* diagnostic criteria to explain risk factors and treatment approaches.

#### **Risk Factors**

While there are important risk factors to note, the presence of risk factors does not necessarily mean a youth will commit suicide. It is important to have a communication system in place that allows the youth to express his or her feelings (CDC, 2015). Talking about suicide is difficult, but with more open communication and less stigmatization, it could be an easier subject to broach (CDC).

The following paragraphs discuss a range of characteristics and factors associated with the risks of youth suicide.

# Individual/Demographic Characteristics

Research on who commits suicide clearly shows that adolescent females attempt suicide at a rate two times higher than adolescent males, but that males are more likely to die from their suicide attempts (CDC, 2015). Of the reported suicides in the 10 to 24 age group, 81 percent of deaths were males and 19 percent were females. Notably, suicidal thoughts and behaviors are relatively rare in childhood but increase drastically during the transition to adolescence (Glenn & Nock, 2014).

Cultural variations in suicide rates also exist. Caucasian females, African American females, and Hispanic females are more likely to seriously consider attempting suicide than Caucasian males, African American males, and Hispanic males, respectively (CDC, 2014). Native American/Alaskan Native youth have the highest rates of suicide-related fatalities (CDC, 2015). A nationwide survey of youth in grades 9 – 12 in public and private schools in the U.S. found that Hispanic youth were more likely to report attempting suicide than their African-American and Caucasian non-Hispanic peers (CDC, 2015).

Evidence of any linkage between socioeconomic status and suicide is sparse and difficult to interpret. Gould, Shaffer, and Greenberg reported that one study examining the socioeconomic status of youth who committed suicide found no difference in status (2003). Another study found that low-income Latino and Caucasian youth and middle-income African American youth had

higher rates of suicide than their counterparts in higher income groups (Gould, Shaffer, & Greenberg, 2003).

Sexual orientation may increase the likelihood of suicide attempts. Among lesbian, gay, bisexual, and transgender (LGBT) adolescents, a history of attempted suicide, impulsivity, prospective LGBT victimization, and limited social supports were linked to increased risk for suicidal ideation (Liu & Mustanski, 2012). However, factors not linked to LGBT status, including those factors outlined in this section, were more likely to lead to suicide than LGBT status alone (Liu & Mustanski).

# Psychological Characteristics

There are a number of psychological disorders associated with increased risk of suicide. These include major depressive disorder, bipolar disorder, substance abuse, and conduct disorder (McKeown, Cuffe, & Schultz, 2006). A study of the most common influencing factors in youth revealed that mental health issues were common; 37 percent of decedents were reported to have a depressed mood and/or current mental health problems prior to their suicide (Karch, Logan, McDaniel, Floyd, & Vagi, 2012). Other studies found than 90 percent of adolescents who commit suicide suffered from at least one psychiatric disorder at the time of death, and that more than half suffered from a psychiatric disorder for at least two years preceding the event (AACAP, 2001; Gould, Shaffer, & Greenberg, 2003).

Depression has been consistently identified as the most common psychological disorder among adolescents who have committed suicide (Gould, Shaffer, & Greenberg; APA, 2013). Additionally, there is a high prevalence of substance abuse among older adolescents, particularly males, who commit suicide (Gould, Shaffer, & Greenberg). There is also a particularly high prevalence of co-occurring depressive disorders and substance abuse among those who commit suicide (Gould, Shaffer, & Greenberg). Another strong predictor is suicidal or homicidal ideation (McKeown, Cuffe, & Schultz; Miller, Rakthus, & Linehan, 2007; Spirito & Overholser, 2003). However, although depression is a strong predictor of suicide ideation, it does not predict which youth with ideation will attempt suicide. Disorders characterized by anxiety, agitation, and poor behavioral control may best predict the transition from ideation to attempt (Nock, Hwang, Sampson, & Kessler, 2010). Other high risk factors include a history of suicide attempts and NSSI. Although NSSI differs from suicidal behaviors because of non-lethal intent, researchers have consistently found that young adults who engage in NSSI are at increased risk for suicidal behavior compared to individuals who do not engage in NSSI (Hamza & Willoughby, 2013).

A recent study was conducted to estimate lifetime prevalence of suicidal behaviors among U.S. adolescents and retrospectively reported mental health disorders with the onset of suicidal behaviors (Nock et al., 2013). This study found that the vast majority of adolescents with these behaviors had preexisting mental disorders. Most suicidal adolescents (greater than 80 percent) had received some form of mental health treatment. In most cases (greater than 55 percent), treatment started prior to onset of suicidal behaviors but failed to prevent these behaviors from occurring. Other research has suggested that less than half of teens who attempt suicide received mental health services in the year prior to their attempt (CDC, 2014).

Another study revealed that most adolescents who are considering suicide or who have attempted suicide do not receive specialized mental health services (Husky et al., 2012). Data was analyzed from the National Comorbidity Survey-Adolescent Supplement (NCS-A), a nationally representative, face-to-face survey of more than 10,000 teens ages 13 to 18. These adolescents were asked whether they had any suicidal thoughts, plans, or actions over a one-year period prior to the survey. They also completed a structured diagnostic interview regarding the full range of mental disorders including mood, anxiety, eating, and anxiety disorders, and whether they had received treatment for emotional or behavioral problems in the past 12 months. The study revealed that suicidal behavior among youth was not only associated with major depression, but also with a range of other mental health problems including eating disorders, anxiety disorders, substance use, and behavior disorders, as well as physical health problems. Between 50 and 75 percent of adolescents reporting suicidal ideation had recent contact with a service provider. However, most only had three or fewer visits, suggesting that treatment tended to be terminated prematurely. Moreover, most teens with suicidal ideation did not receive specialized mental health care

#### Other Risk Factors

There are a number of environmental factors and distressing experiences associated with increased risk of suicide. Youth most at risk of attempting suicide are likely to have recently experienced stressful life events, such as school and work problems, legal problems, and interpersonal conflict (Gould, Shaffer, & Greenberg, 2003). Research suggests that parental divorce and strained parent-child relationships may be factors, after accounting for parent and youth psychopathology (Gould, Shaffer, & Greenberg). One national study reported that 35 percent of youth suicides occurred the same day those youth experienced a crisis, such as a relationship breakup or an argument with a parent (Virginia Department of Health, 2012). Another study found that non-intimate-partner relationship problems, such as issues with parents or friends, preceded over 51 percent of suicides in the study, and a crisis that occurred in the past two weeks preceded 42.4 percent of suicides (Karch et al., 2012).

McKeown, Cuffe, and Schultz (2006) found that the presence of firearms in the home is significantly associated with higher rates of suicide. This is in line with findings from a study that found that firearms account for the greatest number of suicides among older youth and young adults (Gould, Shaffer, & Greenberg, 2003). It is important to note that evidence suggests keeping firearms locked and eliminating unsupervised exposure to firearms may decrease the likelihood of youth suicide involving firearms (Hawton, Saunders, & O'Conner, 2012).

There is strong research evidence to suggest that abuse, both physical and sexual, is associated with increased risk of youth suicide (Gould, Shaffer, & Greenberg, 2003).

Family environment and genetic factors are associated with increased risk for suicide among youth. Additionally, family history of suicide and suicide attempts and parental psychopathology have been associated with increased risk for youth suicide (Gould, Shaffer, & Greenberg, 2003). Even after accounting for the effects of parental psychopathology, a completed suicide by the mother corresponded with a fivefold increase in suicide by offspring, while a completed suicide by the father corresponded with a doubling of suicide rates by offspring (Gould, Shaffer, &

Greenberg). Studies conducted with twins indicate that at least part of this increased suicidal risk could be attributed to genetic factors (Gould, Shaffer, & Greenberg).

While suicide may have a genetic link, exposure to suicide may also increase the likelihood of suicidality, especially in adolescents (Swanson & Coleman, 2013). Some studies have found that the suicide rate among adolescents rises following a highly publicized suicide (Swanson & Coleman, 2013). This likelihood of co-occurring suicide is also referred to as "contagion" or "clustering" (Swanson & Colman). Co-occurring suicide may occur when a classmate or someone with whom the youth has a personal relationship commits suicide (Swanson & Colman). The associations between both ideation and attempts remained for at least two years after the initial exposure, suggesting that intervention and therapy should extend past the first few months following a suicide (Swanson & Coleman).

Studies have also found that sleep disturbance has been associated with an elevated risk of suicide in youth (Emslie et al.; Goldstein et al., as cited by Wolfe, Foxwell, & Kennard, 2014). Assessing sleep may reveal prognostic indicators for suicidal patients, inform clinical decision-making, and guide the development of more precise risk models for suicide. As a warning sign, sleep may thus be a particularly useful factor, and a clinically meaningful intervention tool, to assess in the presence of suicidal ideation and depression (Amitai & Apter, 2012).

Based on a review of 31 articles, researchers found a clear relationship between both bullying (victimization and perpetration) and suicidal ideation and behavior in children and adolescents (Klomek, Sourander, & Gould, 2010). Females were at risk regardless of frequency, whereas males were at higher risk only with frequent bullying. One review cited evidence that bullying victimization is associated with severe baseline psychopathology, as well as individual characteristics and family factors, and that the psychopathology is made significantly worse by the victimization. Being the victim of school bullying or cyberbullying is associated with substantial distress, resulting in lower school performance and school attachment. Suicidal ideation and behavior were greater in those bullied with controlling for age, gender, race/ethnicity, and depressive symptomology (Klomek, Sourander, & Gould).

#### **Assessment**

Every psychological assessment by a clinician should include an assessment of the youth's risk of suicide (Lloyd-Richardson, 2008; Nock, Teper, & Hollender, 2007). Clinicians should keep in mind that, although parents are an important source of information, research has shown that parents tend to underreport their children's NSSI (Nock, Holmburg, Photos, & Michel, 2007), thus making direct assessment critically important. Clinicians should further evaluate every youth who reports thoughts of suicide even though thoughts about death do not always indicate severe psychopathology (Suicide Prevention Resource Center [SPRC], 2011). While suicide ideation is an important indication of risk for suicide (90 percent of youth who attempted suicide had previously reported suicide ideation), not every youth who reports thinking about death, hurting themselves, or ending their lives will attempt suicide (Spirto & Overholser, 2003). The severity of hopelessness, isolation, suicidal ideation, and hesitation to discuss their suicidal thoughts are factors that may differentiate between youth who only contemplate death and suicide and those who, in fact, attempt suicide.

The following guidelines may help assess the level of suicide risk in children and adolescents. These minimum standards should apply in almost all cases, and the youth's medical record should support instances where these standards are not followed. Figure 1 outlines the assessment guidelines for youth suspected of having suicidal thoughts.

#### Figure 1

#### **Youth Suicide Assessment Guidelines**

# Important questions to ask when conducting a youth suicide assessment:

To what degree is the youth in a high-risk group for suicide?

- Is the youth male? (Males are higher risk than females.)
- Has the youth made past suicide attempts?
- Does the youth have a mood disorder? A conduct disorder?
- If male, does the youth use substances?
- Is the youth aggressive or has he or she gotten into fights?
- Does the youth live in a violent community?
- Has the youth engaged in self-mutilation or self-harm in the past?
- If male, is the youth older than 16?

To what degree is a youth who has attempted suicide still at high risk for suicide?

- Is the youth still thinking about committing suicide?
- Did the youth use a method other than ingestion or superficial cutting?
- Is the youth older than 16?
- Is the youth male?
- Is the youth living alone?
- Is the youth currently depressed, manic, hypomanic, severely anxious, or a combination of these?
- Does the youth use substances?
- Is the youth irritable, agitated, delusional, or hallucinating, or has he or she threatened violence against others?

If there is a recent history of suicidal ideation or suicidal behavior, the youth should continue to be monitored.

Sources: American Foundation for Suicide Prevention (AFSP), 2014a; CDC, 2014.

In addition, there are a number of standardized suicide measures that range from long and comprehensive to short screeners. These are described in Table 2.

Table 2
Summary of Assessment Tools

Assessment Tool	Туре	Length	Description
Suicide Ideation Questionnaire (SIQ)	Self- report	Variable	A self-report measure that assesses suicidal thoughts (15 questions for youth in grades 7 – 9; 30 for youth in grades 10 – 12)
High School Questionnaire (SRS and MAPS)	Self- report	Variable	SRS is a short screener for suicidality; MAPS is a 2-hour computer-administered assessment of risk and protective factors
Imminent Danger Assessment	Clinical interview	20 – 30 minutes	Aids clinicians in determining the imminent danger of suicide
Schedule for Affective Disorders (K-SADS)	Clinical interview	2.5 – 3.0 hours	A semi-structured diagnostic clinical interview designed for use with youth that provides a systematic approach for evaluating suicidality
Diagnostic Interview Schedule for Children (DISC)	Clinical interview	1.5 – 2.0 hours	A structured diagnostic clinical interview that can be used to evaluate suicidality
Columbia-Suicide Severity Rating Scale (C-SSRS)	Self- report	Variable	A self-report questionnaire designed to assess severity of suicidal ideation
Suicide Assessment Five- Step Evaluation and Triage (SAFE-T)	Self- report	Variable	A self-report questionnaire designed to assess severity of suicidal ideation
Suicide Behaviors Questionnaire (SBQ-R)	Self- report	Variable	A self-report questionnaire that assesses suicide- related thoughts and behavior
Suicide Assessment Scale	Self- report	Variable	A self-report questionnaire to differentiate suicide attempters from non-attempters

Source: Goldston & Compton, 2007; Substance Abuse and Mental Health Services Administration, n.d.; Posner, et al., 2007.

The Suicide Ideation Questionnaire (SIQ) (Spirito & Overholser, 2003; Goldston & Compton, 2007) is a short self-report questionnaire that includes versions for both younger and older youth and addresses frequency, intensity, duration, and specificity of suicidal thoughts (Spirito & Overholser). The High School Questionnaire is a multi-component questionnaire comprised of the Suicide Risk Screen (SRS) and the Measure of Adolescent Potential for Suicide (MAPS) (Goldston & Compton, 2007). The SRS is a brief measure that assesses past suicidal behavior, suicidal thoughts, and psychopathology (Thompson & Eggert, 1999). MAPS is a computer-administered, self-report measure that can decrease the likelihood of suicide (Spirito & Overholser). This questionnaire assesses the following:

- Direct risk factors, including exposure to suicidal behavior, attitudes/beliefs about suicide, suicide ideation, suicide plans, and past suicide attempts;
- Related risk factors, such as anger, anxiety, depression, and hopelessness; and
- Protective factors, including support, self-esteem, coping, and personal control.

The drawback to the MAPS is its length, which is two hours for administration of the full measure.

Bradley and Rotheram-Borus developed the Imminent Danger Assessment, a clinical interview to assess a youth's imminent risk of suicide (Goldston & Compton, 2007). The interview consists of five tasks, each providing information about the youth's level of risk and ability to remain safe (Goldston & Compton). The tasks ask youth to:

- 1. Identify positive aspects about themselves or the future;
- 2. Use a feeling thermometer to identify emotions, particularly emotions that lead to suicidal thoughts or feelings;
- 3. Generate alternative coping strategies for situations that provoke suicidal feelings and thoughts;
- 4. Identify three supportive individuals from whom they could seek support if they feel that they cannot keep themselves safe; and
- 5. Agree to keep themselves safe and tell someone if they feel unable to keep themselves safe (Goldston & Compton).

The Imminent Danger Assessment provides the clinician with the following information about the youth:

- The youth's degree of hopelessness;
- The youth's ability to identify his or her emotions, which can enable youth to seek support prior to becoming suicidal;
- The youth's reason for saying that he or she is not suicidal (Is the youth truly no longer suicidal or is he or she attempting to avoid further discussion about state of mind or attempting to avoid hospitalization?);
- The youth's ability to identify his or her support system; and
- The youth's ability to cope with suicidal tendencies (Goldston & Compton, 2007).

The Schedule for Affective Disorders (K-SADS) and the Diagnostic Interview Schedule for Children (DISC) are both diagnostic clinical interviews with extensive sections assessing suicidality (Goldston & Compton, 2007). The K-SADS is a semi-structured clinical interview that prompts the clinician to ask about suicidal ideation, non-suicidal self-injurious behavior, history of suicide, and other related topics (Goldston & Compton). The DISC prompts the clinician to ask about the same topics in a more structured manner (Goldston & Compton).

Self-report questionnaires can be useful for adolescents who refuse to talk or have difficulty expressing their thoughts and feelings verbally. One such measure that is sensitive to changes in level of suicidality is the Suicide Assessment Scale. This measure includes factors that have been found to be associated with imminent suicide risk, such as poor frustration tolerance, lack of resourcefulness, sadness, hypersensitivity, and perceived loss of control. The scale has been

shown to differentiate suicide attempters from non-attempters, to be predictive of future suicide, and to be sensitive to change in suicidal state (Posner et al., 2007).

It is well established that the hospital emergency department is a key venue in which to conduct youth suicide screening (Jancin, 2015). Ongoing research is evaluating the feasibility of utilizing an optimal screening tool designed to be used in hospital emergency departments. Routine screening for suicide risk in medical emergency departments would help solve a major challenge to preventing these deaths. Older male teens, who are at highest suicide risk, seldom seek mental health care. However, roughly one-third of adolescents visit the emergency department each year (Jancin).

#### Interventions

Currently there are no treatments that have been deemed evidence-based. Despite limitations in the literature, there is research to support the use of some techniques over others. The following paragraphs summarize the literature regarding treatment focus, crisis management, and ongoing treatment. A summary of interventions and treatments is included in Table 3.

# **Promising Practices in Youth Suicide Prevention**

In a review of the literature on treatments for suicide ideation, suicide attempts, and non-suicidal self-injurious behavior in both youth and adults, treatments that target suicidal behavior directly are shown to be effective (Miller, Rathus, & Linehan, 2007). There is little research to support the effectiveness (as measured by number of suicide attempts or lethality of attempts) of treatments focusing on depression, bipolar disorder, and other underlying disorders associated with suicide (Miller, Rathus, & Linehan). Spirito and Overholser note that, although it is important to treat the underlying psychopathology, such treatments do not necessarily reduce suicidal behavior (2003). In a related finding, a study examining the outcome of two treatments for suicidal females, the treatment that focused directly on suicidal behavior, Dialectical Behavior Therapy (DBT), outperformed the treatment for the control group (community treatment by an expert therapist) in reducing suicide attempts. The treatments, however, did not differ in their effect on depressive symptoms (Linehan et al., 2006).

The SOS Signs of Suicide Prevention Program is a universal, school-based education and screening program that teaches students to recognize warning signs of depression and suicidality in themselves or their peers and to seek help from a trusted adult (Substance Abuse and Mental Health Services Administration [SAMHSA], 2016). The SOS Program is designed for middle school (ages 11 – 13) or high school (ages 13 – 17) students. The screenings within the SOS Program are informational, not diagnostic (Holmberg, 2015). The goal of the screening is to identify students with symptoms consistent with depression and/or suicidality and to recommend a complete professional evaluation. The SOS Program is included on SAMSHA's National Registry of Evidence-based Programs and Practices as promising and is recommended for reducing suicidal thoughts and behavior. The review of the program yielded sufficient evidence of a favorable effect (SAMHSA).

Table 3
Summary of Interventions for Youth Suicide

What Works				
Currently no psychopharmacological treatments meet criteria for a treatment that works.				
Currently no psychological treatments meet criteria for a treatment that works.				
What Seems to Work				
Selective serotonin reuptake inhibitors (SSRIs)	These antidepressants may help reduce suicidal ideation; however, in some individuals they may cause suicidal ideation. Youth taking SSRIs must be closely monitored.			
Cognitive behavioral therapy (CBT) Dialectical behavior therapy (DBT)	These psychotherapies have both shown promise in reducing suicidal ideation in some youth when paired with appropriate medication therapy. Other psychotherapies, such as interpersonal therapy for adolescents, psychodynamic therapy, and family therapy, may also be effective.			
SOS Signs of Suicide Prevention Program	A school-based education and screening program that teaches students to recognize warning signs of depression and suicidality in themselves or their peers.			
Not Adequately Tested				
Gatekeeper training	Involves educating youth, parents, and caregivers in warning signs of suicide to encourage early intervention.			
What Does Not Work				
Tricyclic antidepressants	Not recommended; effectiveness has not been demonstrated, and older tricyclic antidepressants are lethal in overdose quantities.			
No-suicide contracts	Designed as an assessment tool, not a prevention tool. Studies on effectiveness in reducing suicide are inconclusive and their use is discouraged, as they may be interpreted as being coercive or may encourage suicide in some individuals.			

Cognitive behavioral therapy (CBT) has seen promising results in recent years. When paired with the appropriate pharmacological treatments, CBT can be effective in reducing suicidal ideation in youths experiencing negative symptoms (Hawton, Saunders, & O'Connor, 2012).

# Crisis Management

Clinicians should be prepared to hospitalize suicide attempters who express a persistent wish to die or who exhibit symptoms of severe mental disorders. An inpatient stay will allow time for a complete medical and psychiatric evaluation with initiation of therapy in a controlled setting as well as arrangement of appropriate mental health follow-up care (Shain & Committee on

Adolescence, 2016). Discharge should occur only after the following three issues have been addressed:

- 1. Making certain adequate supervision is available;
- 2. Ensuring that the level of suicidality has stabilized; and
- 3. Gaining assurance that the youth's environment will not contain any potentially lethal items, such as guns or medications, by having an explicit conversation with the youth and parent or caregiver about the importance of securing such items (Jacobs et al., 2010).

In addition, immediate treatment, follow-up, and closer monitoring will help the youth transition from the hospital to the home (Salvatore, 2012).

When working with youth at high risk for suicide (particularly during the period following a suicide attempt), therapists must be available 24-hours a day, or must arrange an on-call system or equivalent system. They also must repeatedly assess the youth's state of risk (Spirito & Overholser, 2003). Additionally, parents must be directed to increase the level of supervision provided to the youth.

# Ongoing Treatment

The American Foundation for Suicide Prevention (AFSP) states that psychotherapy, although not in itself an evidence-based practice, is an important component to the treatment of suicidality in youth (2014b). As noted previously, CBT has been found to be a promising treatment for suicide attempters. In addition, DBT has promise for youth with borderline personality disorder and recurrent suicidal ideation and behaviors (AFSP; Hawton, Saunders, & O'Connor, 2012). Moreover, interpersonal therapy for adolescents, psychodynamic therapy, and family therapy are all options when choosing a treatment modality (AFSP). However, as previously noted, research is sparse within this population.

#### Pharmacological Treatment

The U.S. Department of Health and Human Services (2001) has outlined pharmacological interventions thought to be effective in reducing suicide. However, it must be emphasized that youth prescribed any medications must be carefully monitored so that any change in the youth's behavior or any adverse side effects can be immediately reported. New interventions are being developed and tested for the treatment of disorders associated with suicidal behaviors. Since few studies of treatments for mental disorders have included youth with suicidal behaviors, treatments need to be assessed for their potential to reduce suicide. Furthermore, after the youth is thoroughly assessed for any mental disorders, the clinician must tailor the pharmacological interventions to any disorders that have been diagnosed.

#### Antidepressants and the Risk of Suicidal Behavior

According to the AFSP, selective serotonin reuptake inhibitors (SSRIs) may be successful in reducing suicidal ideation and suicide attempts in non-depressed adults with certain personality disorders (2014b). However, it is necessary to closely monitor youth taking SSRIs, as there is some evidence that suggests that SSRIs can increase suicidality in youth and young adults under age 24 (Hammad, Laughren, & Racoosin, 2006). Given concerns about suicidality during

antidepressant treatment, regular and systematic monitoring of suicidality, commencing with a pre-treatment baseline, is recommended instead of relying on spontaneous reports from the patient (Posner, et al., 2007). This may assist in tracking treatment progress and in determining whether any suicidality experienced during treatment is treatment- or disease-specific, thus enabling a better understanding of suicidal state and risk. A more detailed discussion of the use of antidepressants in treating children and adolescents is included in the "Antidepressants and the Risk of Suicidal Behavior" section of the *Collection*.

# Not Adequately Tested

Gatekeeper training involves educating youth, parents, and caregivers in the preliminary warning signs of suicide (Hawton, Saunders, & O'Connor, 2012). Reports from these individuals serves as a frontline defense poised to catch early warning signs and to get affected individuals treatment at earlier stages. By offering this education to many people, it is more likely that early suicidal tendencies will be noticed (Hawton, Saunders, & O'Connor). The available data on the effectiveness of such training is promising, but it is limited in scope and external validity.

# What Does Not Work

No-suicide contracts were explicitly designed to be used for assessment purposes in much the same way as they are used in the *Imminent Danger Assessment* discussed under Assessment section of this chapter (Goldston & Compton, 2007). Due in part to the complications and ethical concerns of conducting research on suicidal patients, the literature on the effectiveness of these contracts is inconclusive (McMyler & Pryjmachuk, 2008). Moreover, study results were varied, with some suggesting that using the contract reduces suicidal behavior and others suggesting that they increase suicidal behavior (McMyler & Pryjmachuk). Goldston and Compton discourage using no-suicide contracts and instead encourage developing a collaborative safety plan with their patients that identifies steps the patient can take during times of high suicidal risk but avoids agreements that could be perceived as coercive.

Tricyclic antidepressants are not recommended for use with suicidal youth, as their effectiveness has not been demonstrated and the possible side effects may outweigh the possible positive outcomes (Wijlaars, et al., 2013). Older-generation tricyclic antidepressants are lethal in overdose quantities and should be avoided in favor of newer generation agents (McCain, 2009).

#### **Overview for Families**

Most teenagers experience stress while growing up. Stressors can include societal pressures to adhere to cultural norms, pressure to succeed, divorce within a family, and financial difficulty. Youth may view suicide as the answer to these stressors if proper treatment is not rendered in time. Families and friends should be aware of the warning signs of suicide and should seek help immediately if they believe a family member or friend is contemplating suicide (AACAP, 2013). The following are risk factors that may increase the likelihood of a suicide attempt:

- Being male, especially over age 16
- Past suicide attempts, especially with methods other than ingestion or superficial cutting
- Mood or conduct disorder
- Substance use, especially among males
- Aggression or fighting
- Living alone or in a violent community
- Currently depressed, manic, hypomanic, and/or severely anxious
- Irritable, agitated, delusional, or hallucinating (AACAP, 2013)

Suicide is the second leading cause of death in youth worldwide. Youth suicide is a growing problem, but proper education, training, and services may help curtail the number of suicides. The biggest challenge affecting treatment is access to high quality care. Early intervention seems to be the greatest determinant of successful treatment. Parents, family members, and friends should be diligent in watching for suicide risk factors and ensuring affected youth receive the treatment they need (AACAP, 2013; Hawton, Saunders, & O'Connor, 2012).

#### **National Crisis Hotlines**

#### The National Suicide Prevention Lifeline

1-800-273-Talk (8255) TTY: 1-800-799-4889

Veterans: Press 1 Spanish: Press 2

#### **Military One Source**

(24 Hour Resource for Military Members, Spouses and Families) 1-800-342-9647

#### **LGBT Youth Suicide Hotline**

Trevor Project 1-866-488-7386

# **Virginia Crisis Centers and Hotlines**

Information provided by Virginia Department of Health Suicide and Youth Violence Prevention Program and local providers.

# **ACTS Helpline**

Serving Dumfries, Manassas City and Manassas Park

Hotline: 703-368-4141 1-800-273-TALK (8255) https://www.actspwc.org/

#### **Concern Hotline**

Clarke Hotline: 540-667-0145 Frederick Hotline: 540-667-0145 Page Hotline: 540-743-3733

Shenandoah Hotline: 540-459-4742 Warren Hotline: 540-635-4357 Winchester Hotline: 540-667-0145

#### The Crisis Center

Bristol Hotline: 800-273-8255 http://www.crisiscenterinc.org/

#### **Crisis Line of Central Virginia**

Lynchburg Crisis Line: 800-947-HELP (4357)

888-947-9747

#### CrisisLine of Norfolk

Norfolk Crisisline 24 Hours / 7 Days: 757-622-1126

#### CrisisLink

Arlington and the Washington Metropolitan area

Hotline: 703-527-4077

#### Madison House - Charlottesville

Hotline: 804-295-8255

http://www.madisonhouse.org/

#### The Raft Crisis Hotline

Blacksburg Emergency & Assessment Crisisline 24 Hours / 7 Days: 540-961-8400

http://www.nrvcs.org/

#### West End Behavioral Healthcare

Richmond City Hotline: 804 819-4100

Martinsville-Henry County 24 Hours / 7 Days: 540-632-7295

Franklin County: 540-489-5490 Patrick County: 540-694-2962 Teenline: 540-634-5005

# **Resources and Organizations**

# **American Association of Suicidology**

1-800-273-TALK (8255)

http://www.suicidology.org/

#### **American Foundation for Suicide Prevention**

https://www.afsp.org/

#### Children's Safety Network

http://www.childrenssafetynetwork.org

# Jason Foundation, Inc.

http://jasonfoundation.com/

# **National Alliance for the Mentally Ill (NAMI)**

http://www.nami.org

#### **National Institute of Mental Health**

https://www.nimh.nih.gov/index.shtml

# **National Organization for People of Color Against Suicide (NOPCAS)**

http://nopcas.org/

#### **National Suicide Prevention Lifeline**

(Toll-Free 24 hours/7 days a week)

800-273-8255

TTY: 1-800-799-4889

http://suicidepreventionlifeline.org

# **Society for the Prevention of Teen Suicide**

http://www.sptsusa.org/

# Suicide Awareness/Voices of Education (SA/VE)

http://www.save.org

# **Suicide Prevention Resource Center (SPRC)**

http://www.sprc.org

# **National Center for Injury Prevention and Control**

Suicide Prevention Activities 800-CDC-INFO (232-4636)

http://www.cdc.gov/violenceprevention/suicide/index.html

#### **Substance Abuse and Mental Health Services (SAMHSA)**

http://www.samhsa.gov

# **National Strategy for Suicide Prevention**

http://actionallianceforsuicideprevention.org/

# **Virginia Department of Health**

Division of Injury and Violence Prevention P.O. Box 2448, 109 Governor Street, Richmond, VA 23219 804-864-7736

# Virginia Suicide Prevention Resource Directory 2016 Edition

http://www.vdh.virginia.gov/livewell/programs/suicide/documents/2016 Suicide Prevention Resource Directory 4th EdFINAL.pdf

# **Youth Suicide Prevention Program (YSPP)**

http://www.yspp.org

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Introduction

Food and Drug Administration Advisory Statement
Effectiveness of Selective Serotonin Reuptake Inhibitors (SSRIs) and the Risk of Suicidality
Limitations of the Research on Suicidality and Antidepressants
Conclusion

#### Introduction

Research indicates that as many as 11 percent of adolescents will experience depression (National Institute of Mental Health (NIMH), n.d.a). Furthermore, according to NIMH, the leading causes of disability in persons aged 15 to 44 years old are depressive disorders. Because depressive disorders (i.e. depression) substantially increase the risk of suicide, much focus has been placed on measuring the effectiveness of treatments for depression. This is particularly true for adolescents because depression in that age group is a strong indicator of suicidal behavior (Treatment for Adolescents with Depression Study (TADS), 2004; Miller, Rathus & Linehan, 2007). Given the serious nature of depression in adolescents, it is imperative that the most effective treatment be made available while minimizing any associated risks (Lock, Walker, Rickert & Katzman, 2005).

Different treatments have been shown to be effective for children and adolescents diagnosed with depression. Certain antidepressant medications, including selective serotonin reuptake inhibitors (SSRIs), have been shown to be effective in as many as 7.5 percent of American children who are taking antidepressants and other behavior-modifying medications (NIMH, n.d.b; Heasley, 2014). However, research has also revealed a possible relationship between suicidal thoughts or actions and the use of SSRIs in children and adolescents with depression. This section will review the current literature on the benefits and risks associated with antidepressant use in children and adolescents with depression. Additional information about effective treatments for youth with depression is located in the "Depressive Disorders" section of the *Collection*.

# **Food and Drug Administration Advisory Statement**

The first accounts of the use of SSRIs in youth with depression were presented to the Food and Drug Administration (FDA) in 2003 (Hammad, Laughren & Racoosin, 2006). The report suggested the possibility that youth diagnosed with major depressive disorder (MDD) who were being treated with paroxetine (a type of SSRI) experienced an increased risk of suicidal thoughts and behaviors (Hammad, Laughren & Racoosin). In response, the FDA reviewed data from the 24 placebo-controlled clinical trials conducted on the use of antidepressants in youth (23 of which were conducted by antidepressant drug manufacturers), specifically looking for the

medication's effects on suicide-related adverse events. This review, as cited by Hammad, Laughren & Racoosin, indicated that:

- 167 events were classified as suicide-related events, although no completed suicides took place in any of the trials; and
- One to three percent of youth taking antidepressants may experience the onset of suicidal thoughts or behaviors or the worsening of suicidal thoughts and behaviors beyond what would be expected from the underlying psychopathology alone, resulting in a doubling of the number of youth experiencing suicidal thoughts or behaviors (2006).

In 2004, the FDA released a statement based on the recommendations of the Psychopharmacologic Drugs Advisory Committee and the Pediatric Drugs Advisory Committee regarding the possibility that increased suicidal thinking and behavior was associated with antidepressant use in pediatric patients (Wolf, 2005). The Advisory Committees' joint statement reflected the findings from controlled pediatric antidepressant trials, which found that antidepressant use in pediatric patients presented an increased risk of suicidality (Wolf).

The FDA then directed manufacturers to add a black-box warning to the health professional label on antidepressants to describe the increased risk of suicidal thoughts and behavior in children and adolescents. The most recent update to the FDA's (2007) warning is outlined in Figure 1.

#### Figure 1

# **Key Points of FDA Black-Box Warning Label For Suicidality and Anti-Depressant Drugs**

- Antidepressants increase the risk of suicidal thinking and behavior in children and adolescents with MDD and other psychiatric disorders.
- Anyone considering the use of an antidepressant in a child or adolescent for any clinical use must balance the risk of increased suicidality with the clinical need.
- Taper dosage to prevent risks of discontinuation syndrome if stopping SSRI treatment.
- Patients who are started on antidepressant therapy should be observed closely for agitation, irritability, clinical worsening, suicidality, or unusual changes in behavior.
- Families and caregivers should be advised to closely observe the patient and to communicate with the prescriber.
- A statement regarding whether the particular drug is approved for any pediatric indication(s) and, if so, which one(s), should be present.

Sources: FDA, 2007; Wolf, 2005.

The FDA also recommends that clinicians should screen for bipolar disorder, because-symptoms of depression may be part of a bipolar episode and antidepressants used alone may trigger a mixed/manic episode in these at-risk patients (FDA, 2007). The FDA warning instructs clinicians prescribing antidepressants to children to inform parents and custodial adults of the black-box warning. Although an advisory statement was issued, the Advisory Committees did have a split decision (15 yes; 8 no) regarding recommendations for a black-box warning for the increased risk of suicidality (Wolf, 2005). In response to the black-box warning, practitioners such as pediatricians and family practitioners have ceased prescribing antidepressants to children and have begun to refer patients to child and adolescent psychiatrists (Virginia Joint Commission on Health Care, 2005). One study including 1.1 million adolescents and 1.4 million young adults using automated health care claims data between 2000 and 2010 found a reduction in antidepressant use of 31 percent for adolescents and over 24 percent for young adults (Lu et al., 2014).

# Effectiveness of Selective Serotonin Reuptake Inhibitors (SSRIs) and the Risk of Suicidality

In evaluating the risk-benefit ratio of using antidepressants, particularly SSRIs, for children and adolescents diagnosed with depression, it is important to have an understanding of the evidence supporting the use of these medicines to counteract suicidal behavior and the risk for suicide in untreated depression. Much of what is known about the benefits of antidepressants in treating youth with depression comes from the Treatment for Adolescents with Depression Study (TADS, 2004). TADS was conducted in spring 2000 through spring 2003 in 13 clinics throughout the United States. TADS examined the short- and long-term effectiveness of one SSRI, fluoxetine, and evaluated its effectiveness, both alone and in combination with psychotherapy, for treating depression in adolescents ages 12 to 17.

TADS compared four different treatment conditions for adolescents with depression: cognitive behavioral therapy (CBT), SSRI therapy (fluoxetine), combined CBT and SSRI therapy, and a placebo (TADS, 2004). TADS's data indicated that there was an increase in harm-related events among adolescents who received fluoxetine as part of treatment. Specifically, adolescents treated with fluoxetine alone were twice as likely to experience a suicidal event compared with those treated with combination therapy or just CBT.

The study team also concluded that, after accounting for benefit and risk, the combination of fluoxetine and CBT was more effective than either treatment alone. Additionally, the SSRI treatment alone was shown to be more effective than the placebo (TADS, 2004). In fact, 61 percent of the youth treated with fluoxetine experienced a reduction in their depressive symptoms, compared to 35 percent for the placebo (Lock, Walker, Rickert & Katzman, 2005).

The primary conclusion of TADS was that fluoxetine treatment for depression in youth is effective, but accompanied with some risks, whereas combining CBT with fluoxetine can improve outcomes and reduce the risks associated with fluoxetine (TADS). Overall, fluoxetine has demonstrated the largest difference between active drug and placebo (American Academy of Child & Adolescent Psychiatry [AACAP], 2007). It is unclear why other SSRIs have not consistently demonstrated effectiveness over placebo, but possibilities include limited effectiveness, poor study design, too-low doses, and insufficient duration of treatment (AACAP).

A recent study conducted a meta-analysis of available data and concluded that out of 14 available antidepressants, the only effective antidepressant for children and adolescents with major depression is fluoxetine (Cipriani et al., 2016). This study found that fluoxetine was the only medication that had reliable research to back its effectiveness when compared with a placebo. However, it is important to note that children and adolescents taking antidepressant drugs should be closely monitored regardless of the treatment chosen, particularly at the beginning of treatment.

Researchers have also looked at the trends in suicide since SSRIs became more commonly used. Olfson, Shaffer, Marcus, and Greenberg (2003) examined the trend in the number of suicides occurring from 1990 to 2000 compared to the number of youth prescribed antidepressants during that period. This study found an inverse relationship between youth suicide and use of antidepressants, and noted that the increased rate of antidepressant use in children and adolescents from 1990 to 2000 was associated with an overall decrease in suicide rates (Olfson et al.). Furthermore, analysis indicated that SSRI use was associated with an even more notable decrease in the suicide rate in high-risk populations; older adolescents and males; and underserved populations, minorities, and low-income youth (Olfson et al.).

Another study comparing the use of CBT, sertraline (an SSRI), CBT plus sertraline, and a placebo in the treatment of youth with anxiety disorders found that, when compared to the placebo, sertraline was not associated with increased suicidality (Walkup et al., 2008). There were no suicide attempts and there were no significant differences in the rate of suicidal ideation between any of the groups (Walkup et al.). This study, however, focused on anxious, rather than depressed youth. Thus, the study does not directly address the risk associated with employing SSRIs in treating depressed youth.

A recent study led by Harvard Medical School (Lu et al., 2014) investigated whether the FDA black-box warnings were linked to changes in antidepressant use, suicide attempts, and completed suicides among young people. The study found that FDA warnings and associated media coverage were associated with decreases in antidepressant use and small increases in suicide attempts. Health care organizations that provided care to 10 million people in 12 states participated in the study. The study noted that, after the FDA's warnings, use of commonly prescribed antidepressants fell by 30 percent in adolescents and 25 percent in young adults. The researcher also found that suicide attempts rose in adolescents and young adults. However, no changes were detected in completed suicides. The researchers cautioned that the study did have limitations because it only measured suicide attempts that received medical attention. Data sources also lacked information on patient outcomes and were limited to the insured population. The researchers concluded that reductions in antidepressant use, generated by concern over suicidal thoughts, might have left a portion of depressed young people without appropriate treatment, which may have caused a small increase in suicide attempts.

A comprehensive analysis of health care data of U.S. residents with depression who initiated antidepressant therapy with SSRIs found a connection between dosage and age. The study found that younger patients who began treatment with higher-than-recommended doses of antidepressants were more than twice as likely to try to harm themselves as those who were initially treated with the same drugs at lower, recommended doses (Miller, Swanson, Azrael, Pate, & Stürmer, 2014). The risk of suicide attempts seemed to be highest in the first 90 days on

the medications (Miller et al.). This analysis did not detect an increase in suicide risk in youth and adolescents treated with recommended drug dosages.

# Limitations of the Research on Suicidality and Antidepressants

When making decisions about the risks associated with antidepressants, particularly SSRIs, it is important to understand the limitations of the research. Suicidality can be very difficult to measure as these events are rare, and the statistical method used to evaluate the risk associated with treating children and adolescents with antidepressants can only be used in studies where a minimum of one adverse event has taken place (AACAP, 2007). Conversely, a study that fails to detect a significant increase in suicidal risk associated with antidepressant medication does not necessarily indicate that there is not a risk (Walkup et al., 2008).

Hammad, Laughren and Racoosin outlined some of the major limitations of the meta-analysis of suicidality in the antidepressant treatment trials (2006). These limitations are:

- Subsequent analysis using the same data increases the uncertainty of the results.
- Analysis is based on short term (4 to 16 weeks) outcomes, making any conclusions about the long-term consequences of antidepressants in youth impossible, although SSRI-related suicidality would be expected to occur within this time frame.
- Measuring suicidal ideation and behavior is inherently difficult due to the distressing nature of the topic.

A separate study noted other potential research limitations, such as the inability to adjust for the severity of the disorder or for antidepressant adherence (Miller et al., 2014). Moreover, it is difficult to know whether the increase in suicidal ideation and behavior represents a true increase or simply a change in the rate of report (Hammad, Laughren & Racoosin). Additionally, all of the trials used by the FDA in making the decision about the black-box warning excluded youth with severe suicidality (Guirgus-Blake, Wright & Rich, 2008). However, the inverse relationship between use of SSRIs and the rate of suicidal behavior is also compelling. Thus, categorical conclusions about the effects of antidepressants on suicidality are difficult to formulate. Knowing the effects of antidepressants on youth with severe suicidality is critical, but more research is required for clearer direction.

#### Conclusion

In summary, the evidence suggests that antidepressants are associated with an increase in suicidal behavior among youth and young adults. There is, however, evidence to suggest that the benefits associated with treating moderately to severely depressed youth with antidepressants outweighs the risks (Hammad, Laughren & Racoosin, 2006; AACAP, 2007).

The results of research conducted by Olfson et al. (2003) suggest that the use of antidepressants has significantly decreased the rate of suicides, yet drug treatment trials indicate that antidepressant use increases the rate of suicidal ideation and behavior among adolescents (Hammad et al., 2006; TADS, 2004). There is also evidence that SSRIs are more effective than placebo medication in treating adolescents with depressive disorders and that the risks associated with SSRIs can be reduced when youth are concurrently receiving CBT (Sharp & Hellings,

2006; TADS). This is a significant finding in the discussion of the effects of antidepressants on suicide since depressive disorders are a significant predictor of suicidal ideation, suicide attempts, and completed suicide (Gould, Shaffer & Greenberg, 2003). Another significant finding is that the period of greatest risk for increased suicidality appears to be in the early stages of SSRI treatment (Lock et al., 2005).

A position paper of the Society for Adolescent Medicine concluded that, after balancing the increased risk of suicidality among adolescents treated with SSRIs with their benefits, the evidence supported the use of SSRIs for adolescents with MDD (Lock et al., 2005). The American Medical Association (AMA) has asserted that its review of various studies supports the view that antidepressants reduce suicidal behavior and completed suicide attempts overall (2005). The organization does acknowledge, however, that the risk of suicidal behavior appears to be highest during the initial course of drug therapy. The AMA's position is that antidepressants should continue to be available with their use guided by sensible clinical judgment (AMA). The AACAP concluded that, with close supervision, the risk-to-benefit ratio supports using SSRIs in the treatment of child and adolescent depression (2007). The Society for Adolescent Medicine, AMA, AACAP, and American Psychological Association (APA) support the use of fluoxetine, the only medication approved by the FDA for the treatment of youth with depression, but recommend close monitoring by both parents and clinicians (FDA, 2004; Lock et al., 2005; AMA, 2005; AACAP, 2007; APA, 2006).

# **Resources and Organizations**

American Academy of Child, & Adolescent Psychiatry (AACAP)

http://www.aacap.org/

**American Academy of Pediatrics (AAP)** 

https://www.aap.org

**American Psychological Association (APA)** 

http://www.apa.org/

**National Institute of Mental Health (NIMH)** 

https://www.nimh.nih.gov

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# ONSUICIDAL SELF-INJURY

Introduction

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### Introduction

Nonsuicidal self-injury (NSSI) is defined as "deliberate, direct destruction or alteration of body tissue, without conscious suicidal intent but resulting in injury severe enough for tissue damage to occur" (Gratz, 2003). NSSI has many names, including self-injury, self-harm, deliberate self-harm, parasuicide, and self-mutilation or cutting. NSSI poses a dire risk for adolescents because of its link to suicide, which ranks as the second most common cause of death among persons ages 10 to 19 years (Shain, 2016). The information contained in this section addresses self-injurious behavior without suicidal intent. For additional information on self-inflicted injury with suicidal intent, see the "Youth Suicide" section of the *Collection*.

NSSI occurs without regard for age, gender, ethnicity, or socioeconomic status; however, much research is centered on adolescents, as this behavior tends to begin during teen years (Boesky, 2002). The rate of NSSI is reported to be between 12 and 35 percent among older adolescents and college students (Miller, Rathus, & Linehan, 2007). The rate of NSSI in a sample of adolescents from the United Kingdom is reported to be 11.2 percent for females and 3.2 percent for males (James, Taylor, Winmill, & Alfoadari, 2008). There is also evidence that these rates may be rising. One study noted that the average annual number of emergency department visits for self-inflicted injuries and attempted suicide more than doubled between 1993 and 2008, and that visits were most common among adolescents aged 15 to 19 years of age (Ting et al., as cited by Cutler et al., 2015).

It is not always clear whether an act of self-harm should be categorized as NSSI or as a suicide attempt because the intended outcome is not certain. Suicide attempts are not always lethal and NSSI may be lethal (Miller, Rathus, & Linehan, 2007). Furthermore, this distinction may not be important since NSSI is one of the strongest predictors of suicide ideation and future suicide attempts (Shain, 2016; Miller, Rathus, & Linehan). One particular study found that these young people have a very high risk for a subsequent successful suicide attempt, with the greatest risk occurring during the period immediately after an episode of self-harm (Bridge et al., as cited by Cutler et al., 2015). As a result, many suicide researchers consider NSSI along with suicidal ideation, suicide attempts, and completed suicide to be occurring along a spectrum and group these behaviors into the category of suicidal behavior (Miller, Rathus, & Linehan). This can be misleading and problematic when it comes to treatment, since suicide attempts and NSSI are thought to serve different functions, with suicide being used as a way to escape from pain and NSSI used to regulate emotion (Miller, Rathus, & Linehan).

# Recent Changes from the DSM-IV to the DSM-5

In 2013, the American Psychiatric Association released the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. NSSI was included in the *DSM-5* as a "Conditions for Further Study." The *Diagnostic and Statistical Manual for Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR)* included NSSI as a symptom of borderline personality disorder (BPD), but the *DSM-5* included it as a separate disorder (Stetka & Correll, 2013). This is based on research that suggests that NSSI can occur independent of BPD, such as in patients with depression or even in those with no other diagnosable psychopathology (Stetka & Correll).

The *DSM-5* is a manual for assessment and diagnosis of mental health disorders and does not include information for treatment of any disorder. In the future, more evidence supporting treatments of disorders with *DSM-5* classifications will be available as clinical studies utilizing *DSM-5* criteria are conducted.

# **Diagnostic Criteria**

NSSI diagnosis requires intentional damage to the surface of the body inflicted by oneself without intent to commit suicide within the past year. Repeated shallow but painful injuries that the youth inflicts on his or her body are the critical feature of NSSI (American Psychiatric Association [APA], 2013). Youth most frequently injure the top of the forearm or thigh with knives, needles, razors, or other sharp objects, and they often create several cuts or scratches in a single session (APA). Commonly, these cuts bleed and leave scars. Injury may also be caused by stabbing, burning, or causing burns by rubbing the skin with another object (APA).

Criteria for NSSI require five or more days of intentional self-inflicted damage to the surface of the body without suicidal intent (APA). The youth engages in the self-injurious behavior with one or more of the following expectations:

- To obtain relief from negative feeling or cognitive state;
- To resolve an interpersonal difficulty; and/or
- To induce a positive feeling state (APA).

The intentional self-injury is associated with at least one of the following:

- Interpersonal issues or negative feelings and thoughts like depression or anxiety;
- Prior to engaging in the act, a period of preoccupation with the intended behavior that is difficult to control; and
- Deliberating the non-suicidal self-injury occurs frequently, even when not acted upon (APA).

Behaviors like body piercing and tattooing, which are socially sanctioned, and nail biting or scab picking are not sufficient to meet an NSSI diagnosis. In order for the youth to be diagnosed with NSSI, the behavior should not occur exclusively during psychotic episodes, delirium, intoxication, or substance withdrawal, and cannot be explained by another medical condition or mental disorder (APA). Moreover, it is important to note that youth who attempt suicide within the past 24 months fall under the "suicidal behavior" diagnosis (Stetka & Correll, 2013).

### **Prevalence**

NSSI typically begins during the early teen years, often between ages 14 to 16, and can carry through to ages 20 to 29 (APA, 2013; Klonsky, 2011). Estimates show that about 18 percent of adolescents engage in NSSI under *DSM-IV* standards (Swannell et al., 2014; Muehlenkamp, Claes, Havertape, & Plener, 2012). The prevalence of females to males in the *DSM-5* rates is closer to 3:1 or 4:1 (APA, 2013). A study of prevalence based upon *DSM-5* criteria show 11.1 percent of females and 2.3 percent of males with NSSI (Zetterqvist, Lundh, Dahlström, & Svedin, 2013). Among community samples of adolescents who met criteria for NSSI, 20 percent reported that at least one of their self-injuries during the last year was a suicide attempt (Zetterqvist, 2015), which can make it difficult to determine the differences between these two problems.

### **Causes and Risk Factors**

Researchers have identified many risk factors associated with NSSI. These risk factors are outlined in Figure 1.

# Associated Psychopathology

The *DSM-5* notes the most common purpose of NSSI is to reduce negative emotions such as tension, anxiety, and self-reproach (APA, 2013). In certain cases, the injury is conceived as a deserved self-punishment to make up for acts that harmed or distressed others (APA). The youth may then report an immediate sensation of relief that occurs during the process (APA).

Adolescents with depressed mood and high anxiety are at higher risk for NSSI (DiFilippo, et al., 2003). Adolescents diagnosed with oppositional defiant disorder (ODD), major depressive disorder, and dysthymia are also significantly more likely to engage in NSSI than adolescents without these particular psychiatric diagnoses (DiFilippo, et al.).

# Figure 1

### **Risk Factors Associated With NSSI**

- Risk taking and reckless behavior childhood sexual abuse
- Childhood physical abuse
- Neglect
- Family violence during childhood
- Family alcohol abuse
- Childhood separation and loss
- Single parent family
- Parental illness or disability
- Poor affective quality and security with childhood attachment figures
- Emotional reactivity
- Emotional intensity
- Hopelessness
- Loneliness
- Anger
- Alcohol use

Sources: Gratz, 2003; DiFilippo, Esposito, Overholser, & Spirito, 2003; Laye-Gindhu & Schonert-Reichl, 2005.

Additional studies have shown that adolescents with any comorbid condition are at increased risk of NSSI and those with greater than two comorbid conditions have nearly three times the odds (Cutler et al., 2015). The specific comorbid conditions of obesity and alcoholism were associated with increased risk of NSSI (Cutler et al.).

Research conducted on adults indicates that NSSI also occurs in 80 percent of those diagnosed with borderline personality disorder (BPD) (Miller, Rathus, & Linehan, 2007). The characteristics of individuals with BPD and those who engage in repeated acts of NSSI overlap substantially. For example, Linehan (1993) asserts that adults diagnosed with BPD are particularly prone to hopelessness and may see suicidal behavior, with or without the intent to die, as the only option for managing their chaotic and distressing lives. For some adolescents who engage in NSSI, development of BPD may carry over into adulthood (American Academy of Child & Adolescent Psychiatry [AACAP], 1999), although some youth will outgrow their self-injurious behavior. The *DSM-5* separates NSSI from BPD because BPD does not occur in all individuals with NSSI, the motivation for self-injury varies, and different neurotransmitters are involved in the two disorders. In BPD, self-injury is manifested in disturbed aggressive and hostile behaviors, whereas those with NSSI alone often injure based on variability in closeness, collaboration, and positive relationships (APA, 2013).

Suicidal behavior disorder, discussed in the Youth Suicide section of this *Collection*, is connected to NSSI because NSSI may evolve into suicidality. Individuals who self-injure may eventually attempt suicide, and a greater number of self-harm methods previously attempted suggest a greater likelihood of suicidal intent (APA, 2013). Thus, nonsuicidal self-injury can be a

warning sign for potential suicide attempts in the future. Other forms of self-injury discussed in this *Collection* are trichotillomania and excoriation (skin-picking) disorder, discussed in the Obsessive-Compulsive and Related Disorders section. Stereotypic self-injury, such as head banging, self-biting, or self-hitting, may be connected to developmental delay (APA).

# Familial and Biological Causes

In a review of the literature on NSSI and BPD, Crowell, Beauchaine and Lenzenseger (2008) indicate that there is a clear familial component to NSSI, but point out that it is still uncertain whether this is due to genetics, environment, or both. Relatives of individuals who have engaged in NSSI are three times more likely to engage in such behavior themselves (Crowell, Beauchaine, & Lenzenseger). Additionally, Linehan (1993) states that patients diagnosed with BPD often grow up in environments where emotional expression goes unrecognized or is punished, the outcome being that emotional regulation skills are underdeveloped. The significant overlap between those who engage in NSSI and those diagnosed with BPD suggests that invalidating childhood environments put youth at risk for NSSI.

There is consistent evidence to support a genetic component for impulsivity, affective instability, and aggression—all risk factors for NSSI (Crowell, Beauchaine, & Lenzenseger, 2008). Research conducted on the possible causes of NSSI has focused on the neurotransmitters serotonin and dopamine; however, these studies have largely focused on adult populations (Crowell, Beauchaine, & Lenzenseger). One study of self-injuring adolescents found reduced levels of peripheral serotonin and others have found decreased dopamine level in suicide attempters (Crowell, Beauchaine, & Lenzenseger). Additionally, studies have supported the role of the neurotransmitters acetylcholine and norepinephrine in emotional stability (Crowell, Beauchaine, & Lenzenseger).

### Assessment

Research tools for assessing NSSI in community populations are few and are either limited in the scope of NSSI characteristics assessed or included as part of suicide assessment (Whitlock, Exner-Cortens, & Purington, 2014). However, assessment of NSSI is a critical and important component of any psychological assessment, and assessment tools may change, as the DSM-IV did not include diagnostic criteria for NSSI (Lloyd-Richardson, 2008; Nock, Teper, & Hollender, 2007). Recent years have seen the development of a number of questionnaires and semistructured and structured interviews that aid in the assessment of the prevalence, frequency, severity, and function of self-injurious behavior (e.g., Self-Injurious Thoughts and Behaviors Interview, Self-harm Behavior Questionnaire, Lifetime-Suicide Attempt Self-Injury (L-SASI) Interview) (Lloyd-Richardson). While parents are an important source of information, research has shown that parents tend to underreport their child's suicidal ideation and NSSI, making direct assessment critical (Nock, Holmburg, Photos, & Michel, 2007). Mental health professionals should inquire about suicide ideation, suicide attempts, and NSSI with all adolescents in high-risk groups. Individuals who engage in NSSI do so for a wide variety of reasons and understanding these reasons is an important step in effective treatment, particularly since such analysis guides treatment (Lloyd-Richardson). Suggested assessment tools for NSSI are included in Table 1.

Table 1
Suggested Assessment Tools for Nonsuicidal Self-Injurious Behavior

Measure Type	Name of Measure	What is Measured
Structured Interview	Self-Injurious Thoughts and Behaviors Interview	The presence and frequency of suicidal behavior, including NSSI
Self-Report	<ul> <li>Suicidal Behavior Questionnaire:</li> <li>SBQ-14, a 14-item version for adolescents, and</li> <li>SBQ-C, a 4-item version for children</li> </ul>	Suicidal ideation, behavior and NSSI
Self-Report	Functional Assessment of Self- Harm	Frequency, type, and intent of NSSI

Sources: Nock, Holmburg, Photos, & Michel, 2007; Goldston & Compton, 2007.

### **Treatment**

NSSI represents a pattern of behavior, rather than a single isolated event, and is perpetuated through both positive and negative reinforcement (Linehan, 1993; Gratz, 2003; Miller, Rathus, & Linehan, et al., 2007). For example, NSSI is positively reinforced when the adolescent experiences a sense of control or relaxation following self-harm (Gratz). NSSI is negatively reinforced when the adolescent experiences distressing or unpleasant emotions and or thoughts—for example, sadness, loneliness, emptiness, emotional pain, and self-hatred—following self-harm (Gratz, Linehan). Therefore, Miller, Rathus, and Linehan suggest that interventions aimed at reducing NSSI should focus on strengthening emotion regulation skills. This approach varies from interventions aimed at reducing suicidal behavior, which instead help the adolescent identify reasons for living. Proper assessment is critical to effectively treating NSSI. Table 2 lists treatments for NSSI.

Historically, youth who self-harm, chronic suicide attempters, and individuals with BPD have been considered highly resistant to treatment (Muehlenkamp, 2006). In recent years, however, there have been major developments for adolescents diagnosed with these disorders. A review of the literature outlining treatment for suicidal behavior (suicide ideation, suicide attempts, and NSSI) shows that treatments that address the problem behaviors directly consistently outperform treatments that conceptualize suicidal behavior as a symptom and treat the underlying psychopathology (Miller, Rathus, & Linehan, et al., 2007).

# Psychosocial Treatment

Cognitive behavioral therapy (CBT) is one treatment for NSSI that has been tested. Two other promising treatments have been studied in greater depth: problem solving therapy and dialectical behavioral therapy (DBT) (Muehlenkamp, 2006). Research on the effectiveness of problem solving therapy in treating NSSI shows promise, but the study results are too sparse to support a

strong conclusion regarding its effectiveness (Muehlenkamp). The premise of CBT for NSSI is to reduce NSSI behaviors by helping clients develop new coping skill sets, address motivational obstacles during treatment, and promote skill generalization outside the therapy setting (Muehlenkamp). DBT has been demonstrated as effective for the treatment of BPD, suicidality, and NSSI among adults and thus has received a lot of attention. When treating adolescents who engage in suicidal behavior, with and without intent to die, DBT has consistently led to significant reductions in self-injurious behavior, but has not demonstrated significantly better outcomes than those in the comparison group (Nock, Teper, & Hollender, et al., 2007; Peterson, Freedenthal, Sheldon, & Andersen, 2008). Thus, although DBT is an effective treatment for adults with NSSI and BPD, its effectiveness for children and adolescents is still being tested.

Table 2
Summary of Treatments for Nonsuicidal Self-Injurious Behavior

What Works			
There are no evidence-based practices at this time.			
What Seems to Work			
Cognitive behavioral therapy (CBT)	CBT involves providing skills designed to assist youth with affect regulation and problem solving.		
Dialectical behavior therapy (DBT)	DBT emphasizes acceptance strategies and the development of coping skills.		
Not Adequately Tested			
Problem solving therapy	Designed to improve an individual's ability to cope with stressful life experiences.		
Pharmacological treatment	Evidence of the effectiveness of the use of medications, such as high-dose SSRIs, atypical neuroleptics, and opiate antagonists, is limited. In addition, some medications have been shown to increase suicidal ideation in children and adolescents.		
Hospitalization	Because effectiveness is not consistently demonstrated, should be reserved for youth who express intent to die.		

# Pharmacological Treatment

Medications such as selective serotonin reuptake inhibitors (SSRIs) and opiate antagonists have been studied, but evidence that supports their effectiveness is inconclusive (Martinson, 1998). To date, it appears that the most promising treatments are high-dose SSRIs and, in some cases, atypical neuroleptics (Martinson). Fluoxetine shows the most promise in NSSI treatment, based on its effect on serotonin, but its efficacy does not meet evidence-based standards (Smith, 2008). Because evidence is so limited, pharmacological treatment of NSSI is not considered an evidence-based treatment at this time. Additionally, since the *DSM-5* notes that different neurotransmitters are affected by NSSI and BPD, pharmacological treatment may further change in the future (APA, 2013). A more detailed discussion of the use of antidepressants in treating

children and adolescents is included in the "Antidepressants and the Risk of Suicidal Behavior" section of this *Collection*.

# Hospitalization

Historically, hospitalization has been the standard treatment for NSSI, but it is the most expensive option, and evidence of its effectiveness has not been consistently demonstrated (Muehlenkamp, 2006). Research focused on suicidal ideation and suicide attempts indicates that the most dangerous time for youth following hospitalization for suicidal behavior is between six months to a year, during which 10 to 18 percent of youth will attempt suicide (Prinstein et al., 2008). As a result, outpatient mental health providers are the most likely choice for youth, with hospitals admissions typically reserved for adolescents with NSSI who express intent to die (Muehlenkamp).

# Recommended Elements of Treatment

Clinical researchers have identified treatment components for NSSI that recur in the research. While these treatment elements do not have the clinical trials and studies that classify them as evidence-based, they do represent an emerging clinical consensus. These treatment elements are described in this section.

An important treatment element for youth who have engaged in NSSI is the establishment of a strong therapeutic alliance between the youth and the service provider. Once the alliance is formed, an important treatment goal is to reduce and ultimately eliminate NSSI by replacing it with healthier coping skills (Muehlenkamp, 2006). Another recommended component is the establishment and maintenance of meaningful connections between adolescents and their families (Muehlenkamp). However, the treatment trials of DBT for adolescents have not consistently included a family component and, to this point, there has not been a study comparing DBT for adolescents with and without the family therapy component. Thus, data regarding the importance of family involvement in the treatment of adolescents who engage in NSSI is still being gathered.

# **Cultural Considerations**

In a review of the literature on ethnic differences among self-harming adolescents, researchers in Great Britain found no significant difference between the rate of NSSI among Asian and Caucasian adolescents (Goddard, Subotsky, & Fombonne, 1996). A study comparing the ethnic and racial distribution of adolescents who reported NSSI and the ethnic and racial distribution in the population found no significant difference between the rates at which adolescents from various ethnic groups were referred to for psychiatric services following acts of deliberate self-harm (Goddard, Subotsky & Fombonne). In the United States, there are studies that have reported that African American and Latino adolescents have higher rates of suicide attempts than Caucasian adolescents, but it is unclear whether this holds true for NSSI (Spirito, 2003).

When comparing youth in the United States, Italy, and the Netherlands, youth in the United States are more likely to have comorbid NSSI and substance use (Gilettaa et al., 2012). There are no discernable differences in prevalence between youth in the United States and those in Germany (Plener et al., 2009). The U.K., Ireland, Belgium, Norway, and Australia all have

similar prevalence rates, and Hungary and the Netherlands have lower rates of NSSI (Whitlock & Rodham, 2013).

This prevalence, or at least the convention of NSSI, may increase with websites like YouTube. Studies investigating the pervasiveness of NSSI videos online revealed 2,140 videos in 2009 and over 5,000 in 2012 (Purington & Whitlock, 2010; Lewis, Heath, Michal, & Duggan, 2012). A Google search in 2009 revealed more than 15 million results, and almost 87 million in 2014 (Purington & Whitlock, 2010).

# **Overview for Families**

The terms self-injury, parasuicide, deliberate self-harm, self-abuse, self-mutilation, self-inflicted violence, or cutting is the deliberate harming of one's body, resulting in tissue damage, without the intent of suicide. It does not include culturally-sanctioned activities, including tattoos or actions within a religious or cultural ritual. Family members can look for signs of self-injury, including:

- Scratching (excoriation)
- Cutting
- Burning
- Hitting or biting oneself
- Ingesting or embedding toxic substances or foreign objects
- Hair pulling
- Interfering with wound healing

This list is not exclusive, and families may also see other types of personal harm. Children who self-harm may exhibit more than one form of self-injurious behavior (Self-Injury Foundation, n.d.).

Often, family members wonder why youth engage in self-harm. Some reasons may include the following:

- Distracting from emotional pain (this is most common)
- Punishing oneself
- Relieving tension
- Sense of being real by feeling pain or seeing evidence of injury
- Numbing feelings; to not feel anything
- Experiencing a sense of euphoria
- Communicating pain, anger, or other emotions to oneself or others
- Nurturing oneself through the caring for wounds (Self-Injury Foundation, n.d.)

Studies show that females self-injure more frequently than males. While self-injury typically begins in adolescence, it is not limited to youth or teens, and it may continue into adulthood.

# **Resources and Organizations**

# American Academy of Child & Adolescent Psychiatry (AACAP)

Self-Injury in Adolescents

http://www.aacap.org/aacap/families\_and\_youth/facts\_for\_families/fff-guide/Self-Injury-In-Adolescents-073.aspx

# **Cornell Research Program on Self-Injurious Behaviors (CRPSIB)**

http://www.selfinjury.bctr.cornell.edu/

# Mental Health America (MHA) (formerly National Mental Health Association)

http://www.mentalhealthamerica.net/

# **National Alliance of Mental Health**

Self-Harm

https://www.nami.org/Learn-More/Mental-Health-Conditions/Related-Conditions/Self-harm

# **National Institute of Mental Health**

https://www.nimh.nih.gov

# **National Suicide Prevention Lifeline**

1-800-273-TALK (8255)

https://suicidepreventionlifeline.org/

# S.A.F.E. Alternatives (Self-Abuse Finally Ends)

800-DON'T CUT (366-8288)

https://selfinjury.com/

# **Self-Injury Foundation**

P.O. Box 962 – South Haven, MI 49090

http://www.selfinjuryfoundation.org/index.html

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# JUVENILE OFFENDING

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# Introduction

Mental health disorders are common among youth involved in the juvenile justice system. The National Center for Mental Health and Juvenile Justice (NCMHJJ) and the Council of Juvenile Correctional Administrators conducted a study of the prevalence of mental health disorders in youth involved in the juvenile justice system. According to this study, 70 percent of these youth met the criteria for at least one mental health disorder, and approximately a quarter of all youth in the juvenile justice system experienced a mental health disorder so severe that they required critical and immediate treatment (McGarvey, 2012; NCMHJJ, 2006). Further studies reveal that approximately 50 to 75 percent of the 2 million youth encountering the juvenile justice system met criteria for a mental health disorder (Underwood & Washington, 2016). Moreover, in previous studies of juvenile offender detention facilities, two-thirds of males and three-quarters of females in these facilities were found to meet criteria for at least one mental health disorder, and an additional one-tenth also met criteria for a substance use disorder (Underwood & Washington). Such numbers are particularly troubling when compared to the general youth population, among which only about 20 percent of youth suffer from a diagnosable mental health disorder.

In Virginia, more than 92 percent of juveniles committed to the Department of Juvenile Justice have significant symptoms of attention-deficit/hyperactivity disorder (ADHD), conduct disorder (CD), oppositional defiant disorder (ODD), or a substance use disorder (Virginia Department of Juvenile Justice [VDJJ], 2016). More than 64 percent of admitted juveniles had significant

symptoms of other mental health disorders, with a higher percentage of females (89.5 percent) than males (62.7 percent) having significant symptoms of a mental health disorder (excluding those disorders previously listed). Moreover, a higher percentage of females (73.7 percent) than males (60.3 percent) had also been prescribed psychotropic medication (VDJJ).

Youth with mental health disorders may have symptoms involving impulsiveness, anger, and cognitive misperception that can make them a greater risk to themselves or others, especially if they are under the stress associated with an offense and arrest (Grisso, 2008). Among youth who are detained, a significant number are likely to have mental disorders that create unmanageable behaviors. Thus, it is no surprise that youth with mental disorders contribute disproportionately to detention populations.

Of youth involved with the juvenile justice system, approximately 15 to 30 percent have been diagnosed with depression or dysthymia, 13 to 30 percent have been diagnosed with ADHD, three to seven percent have been diagnosed with bipolar disorder, and 11 to 32 percent have been diagnosed with posttraumatic stress disorder (PTSD) (Underwood & Washington, 2016). Grisso (2008) also noted that both CD and substance use disorders are quite prevalent in youth. The psychiatric disorders seen most commonly in juvenile offenders are listed in Figure 1.

# Figure 1

# Most Common Mental Health Disorders and Issues Seen Among Juvenile Offenders

- Conduct disorder (CD)
- Oppositional defiant disorder (ODD)
- Major depressive disorder
- Dysthymic disorder
- Manic episodes
- Attention-deficit/hyperactivity disorder (ADHD)
- Posttraumatic stress disorder (PTSD)
- Substance use disorders

Sources: Underwood & Washington, 2016; Grisso, 2008.

In 2013, the American Psychiatric Association (APA) released the fifth edition of the *Diagnostic* and Statistical Manual of Mental Disorders (DSM-5) to replace the fourth text revision (DSM-IV-TR). The DSM-5 is a manual for assessment and diagnosis of mental health disorders and does not include information for treatment of any disorder (APA, 2013). In the future, more evidence supporting treatments of disorders with DSM-5 classifications will be available as clinical studies utilizing DSM-5 criteria are conducted. As a result, this Collection will reference studies that utilize DSM-IV-TR diagnostic criteria to explain symptoms and treatments.

# **Risk and Protective Factors**

Several risk factors predict violent juvenile offending. However, one must take care not to assume that a risk or protective factor will predict particular outcome. No single risk factor leads a young person to delinquency. Risk factors "do not operate in isolation and typically are cumulative: the more risk factors that [youth] are exposed to, the greater likelihood that they will experience negative outcomes, including delinquency" (Kendziora and Osher, 2004). The factors that place youth more at risk for perpetuating violence are identified by the Centers for Disease Control (CDC) and include:

- Impulsiveness
- Youth substance use
- Antisocial or aggressive beliefs and attitudes
- Low levels of school achievement
- Weak connection to school
- Experiencing child abuse and neglect
- Exposure to violence in the home or community
- Involvement with delinquent peers or gangs
- Lack of appropriate supervision
- Parental substance abuse
- Parental or caregiver use of harsh or inconsistent discipline (Farrington, Ttofia, & Piquero, 2016; David-Ferdon et al., 2016)

The presence of more than one mental health disorder also serves as a risk factor for juvenile offending, placement within the juvenile justice system, and increased likelihood of recidivism (Cottle, Lee, & Heilbrun, 2001). Furthermore, certain mental health disorders, such as affective disorders (depression, bipolar disorder, and anxiety disorders) and substance use disorders, increase risk (Schubert, Mulvey, & Alderfer, 2011). The findings of a study conducted by the Research and Training Center on Family Support and Children's Mental Health (2001) indicated that children at risk for institutional placement were placed according to the primary type of dysfunction they displayed, with behaviorally disordered children being incarcerated and emotionally disordered children being placed into the state mental health system. A more recent study found that among youth in the juvenile court delinquent population, those diagnosed with bipolar disorder were eight times more likely to be placed in detention for committing a personal crime (a violent crime against an individual) than those who did not have this disorder (Stoddard-Dare, Mallett, & Boitel, 2011). Surprisingly, this study also found that youth with either ADHD or a CD were somewhat less likely to commit a personal crime and be subsequently placed in detention. The study's authors hypothesize that, because the diagnostic criteria used to determine diagnosis and severity was based observable behaviors (e.g., hyperactive behaviors, fidgety, and/or nervous for ADHD and aggression and/or violations of norms for CD), and because ADHD and CD symptoms are often readily observable and frequently impact or distract others, interventions to assist these youth may have been pursued earlier and on a more consistent basis (Stoddard-Dare, Mallet, & Boitel).

The NCMHJJ (2005) identified gender-specific risk that may also influence high-risk behaviors linked to delinquency. There is evidence that females in the juvenile justice system are more

likely to have experienced certain types of trauma (e.g., sexual abuse and rape) than males (Zahn et al., 2010). Accordingly, these differences have also been noted as mental health risk factors for delinquency. For example, females in the juvenile justice system who have mental health disroders such as depression, anxiety, and PTSD may also have life stressors and experiences of victimization that are linked to these disorders (Zahn et al.).

Carr and Vandiver (2001) have identified a variety of protective factors that are associated with lower rates of recidivism among youth offenders. These protective factors are personal, familial, social, and academic (Carr & Vandiver). For example, juveniles with a lower risk for recidivism reported being happier with themselves, had more positive attitudes toward school rules and law enforcement, and had more structure and rules within their homes. Other protective factors outlined by David-Ferdon (2016) include healthy problem-solving and emotional regulation skills as well as higher rates of school readiness and academic achievement. Positive parent-youth relationships, in which parents set consistent, developmentally appropriate limits and demonstrate interest in their children's education and social relationships, were also associated with healthy youth development and the prevention of violent behavior (David-Ferdon et al.). Additional factors that contribute to healthy adolescent development and decreased aggressive behaviors include youth feeling connected to their schools, experiencing academic success, and having positive relationships with teachers, other caring adults, and prosocial and nonviolent peers (David-Ferdon et al.).

# **Screening and Assessment**

The following is taken from the NCMHJJ (2016). Although mental health disorders are common among youth involved in the juvenile justice system, these mental health problems frequently go undetected, increasing the likelihood that these juveniles will have persistent difficulties. Screening and assessment of juvenile offenders helps determine how the juvenile justice system can address their treatment needs. Screening also identifies youth who may require further attention or may have serious needs. Being "screened in" on a screening tool does not necessarily mean that a youth actually has a diagnosable mental health or substance use disorder or a significant risk of harming him/herself or someone else. However, it does indicate that that further follow-up is necessary to determine the presence of a suspected condition.

Assessment tools may help officials and mental health professionals determine if a child who has come in contact with the juvenile justice system displays signs of mental disturbance or emotional distress (Heilbrun, Cottle, & Lee, 2001). Assessments are conducted to provide a more detailed description of:

- The youth's history;
- Clinical needs:
- Functioning across several domains (e.g., family, peers, school);
- Risk and protective factors; and
- Recommendations for management or treatment.

As noted by Hammond (2007), another important purpose of assessment is to address the legal issues surrounding a juvenile's competency to understand the adjudicatory process and to

thoughtfully participate in and make decisions during that process. Incompetence to stand trial is typically related to a mental disorder or developmental disability.

Table 1 lists the assessment tools described in this section.

Table 1

Evidence-based Assessment Tools Used with Juvenile Offenders

Description
Estimates a youth's risk of recidivating and need for services.
Includes a prescreen section that identifies moderate- or high-risk youths, who are then administered the full assessment.
Estimates the risk of youth committing a specific offending behavior.
Measures symptoms on seven scales pertaining to areas of emotional, behavioral, or psychological disturbance, including suicide ideation.
This 25-item self-report screening instrument is used to assess suicidal ideation in adolescents.
This 20-item behavioral health screening tool is designed to identify adolescents in need of more detailed assessment for substance use or mental disorders.
This self-report, computerized tool assesses youth for various mental health disorders.

Sources: OJJDP, 2015; Vincent, 2011.

Below are three examples of risk/needs assessments that illustrate the variety of formats that assessment tools can take, as outlined by the Office of Juvenile Justice and Delinquency Prevention (OJJDP) (2015). The Youth Level of Services/Case Management Inventory (YLS/CMI) is an example of an assessment instrument that estimates a youth's risk of recidivating and need for services based on a variety of factors. The Youth Assessment and Screening Instrument (YASI) is an example of an instrument that includes a prescreen section that identifies moderate- or high-risk youth, who are then administered the full assessment. The Structured Assessment of Violence Risk in Youth (SAVRY) is an example of an assessment designed to estimate the risk of youth committing a specific offending behavior (i.e., violent acts).

The information in the following paragraphs is taken from Vincent (2011). There are several mental health screening tools that can be used by juvenile justice personnel. The Massachusetts Youth Screening Instrument – Version 2 (MAYSI-2) measures symptoms on seven scales pertaining to areas of emotional, behavioral, or psychological disturbance, including suicide ideation. The Suicidal Ideation Questionnaire (SIQ) is a 25-item self-report screening instrument

used to assess suicidal ideation in adolescents. It can be administered individually or in a group setting. The Global Appraisal of Individual Needs – Short Screener (GAIN-SS) is a 20-item behavioral health screening tool designed to identify adolescents in need of more detailed assessment for substance use or mental disorders. Many studies have been conducted to demonstrate that this tool accurately identifies drug and alcohol problems. The Voice-Diagnostic Interview Schedule for Children (Voice-DISC) is a self-report, computerized tool. There are also several more comprehensive mental health assessment tools that are used in many youth systems and have research evidence that supports their validity.

# **Comorbid Disorders**

Information in this section is taken from Teplin et al. (2006). Research conducted of youth in detention indicates substantial comorbidity of mental health disorders in both females and males. The Northwestern Juvenile Project, a large-scale study of the mental health needs of delinquent youth, revealed that more than half of incarcerated females (56.5 percent) and almost half of males (45.9 percent) had more than one mental health disorder. The study also noted that only one-fifth of youth in detention had just one mental health disorder. Nearly one-third of females (29.5 percent) and males (30.8 percent) had substance use disorders and ADHD or disruptive behavior disorders, and approximately half of these youth also had anxiety disorders, affective disorders (e.g., depression, bipolar disorder, or anxiety disorder), or both. Disorder patterns also varied by gender. For instance, significantly more females (47.8 percent) than males (41.6 percent) had two or more of the following types of disorders: affective disorders, anxiety disorders, substance use, and ADHD or disruptive behavior. Moreover, more females (22.5 percent) than males (17.2 percent) had three or more types of disorders.

The comorbidity of substance use disorders is also of particular concern. Among the disorders assessed, juveniles who were detained were more likely to have substance use plus ADHD or disruptive behavior disorders than any other combination. Half of these detainees also had an affective or anxiety disorder. Females had higher rates than males of many single and comorbid psychiatric disorders, including major depressive episodes, some anxiety disorders, and substance use disorders other than alcohol and marijuana (e.g., cocaine and hallucinogens). Solutions for treating co-occurring substance use disorders for youth in the justice system are complicated, particularly because adolescents often return to the peer, family, and community environments that initially supported and promoted their substance use.

### **Treatments**

Heightened awareness of mental health disorders has led to increased research and new treatment practices in the juvenile justice system. Among delinquent juveniles who receive structured, meaningful, and sensitive treatment, recidivism rates are 25 percent lower than those in untreated control groups. Highly successful programs reduce rates of recidivism by as much as 80 percent (Coalition for Juvenile Justice, 2000). Youth within the juvenile justice system have different mental health needs that require differing levels of care. This necessitates an effective screening and assessment processes, as well as varied treatment options (Underwood & Washington, 2016). It is also important to note that youth involved in the juvenile justice system also have specific criminogenic risks and needs. Interventions that reduce the risk of re-offending may be

broader than mental health treatments outlined in the paragraphs that follow and may be more appropriate for juveniles with acute needs and risk factors.

Effective interventions incorporate several treatment components that are discussed in the following paragraphs. Table 2 outlines these treatments.

Table 2
Summary of Treatments for Juvenile Offenders

What Works		
Multisystemic therapy (MST)	An integrative, family-based treatment with a focus on improving psychosocial functioning for youth and families.	
Functional family therapy (FFT)	A family-based program that focuses on delinquency, treating maladaptive and "acting out" behaviors, and identifying obtainable changes.	
Treatment Foster Care Oregon (TFCO)	As an alternative to corrections or residential treatment, TFCO places juvenile offenders with carefully trained foster families who provide youth with close supervision, fair and consistent limits, consequences, and a supportive relationship with an adult. The program includes family therapy for biological parents, skills training and supportive therapy for youth, and school-based behavioral interventions and academic support.	
What Seems to Work		
Family centered treatment (FCT)	FCT seeks to address the causes of parental system breakdown while integrating behavioral change. FCT provides intensive in-home services and is structured into four phases: joining and assessment, restructuring, value change, and generalization.	
Brief strategic family therapy	A short-term, family-focused therapy that focuses on changing family interactions and contextual factors that lead to behavior problems.	
Aggression replacement therapy (ART)	A short-term, educational program that focuses on anger management and provides youth with the skills to demonstrate non-aggressive behaviors, decrease antisocial behaviors, and utilize prosocial behaviors.	
Cognitive behavioral therapy (CBT)	A structured, therapeutic approach that involves teaching youth about the thought-behavior link and working with them to modify their thinking patterns in a way that will lead to more adaptive behavior in challenging situations.	
Dialectical behavior therapy	A therapeutic approach that includes individual and group therapy components and specifically aims to increase self-esteem and decrease self-injurious behaviors and behaviors that interfere with therapy.	

Sources: NCMHJJ, 2002; Sullivan, Bennear, & Painter, 2009; Henggeler & Schoenwald, 2011; AACAP, 2013; & Underwood & Washington, 2016.

# Home and Community-Based Models

Although several of the following treatment approaches may be applied and utilized in the institutional setting, this discussion refers to the application of these approaches in a community setting.

# Multisystemic Therapy

Multisystemic therapy (MST) is an integrative, family-based treatment that focuses on improving psychosocial functioning in youth and families with the goal of reducing or eliminating the need for out-of-home placements (Henggeler et al., 2009). MST addresses the numerous factors that shape serious antisocial behaviors in juvenile offenders while focusing on the youth and his or her family, peers, school, and neighborhood/community support (Henggeler, as cited by the NCMHJJ, 2002; Coalition for Evidence-Based Policy, n.d.). The underlying premise of MST is that the behavioral problems in children and adolescents can be improved through the interaction with or between two or more of these systems.

MST has an extensive body of research to support its effectiveness in juveniles who have emotional and behavioral problems. It is considered to be an effective, intensive, community-based treatment for justice-involved youth (Zajac, Sheidow, & Davis, 2015). Evaluations have shown reductions of up to 70 percent in long-term rates of re-arrest, reductions of up to 64 percent in out-of-home placements, improvements in family functioning, and decreased mental health problems (National Mental Health Association, NMHA [now Mental Health America, MHA], 2004).

# Functional Family Therapy

Functional family therapy (FFT) is a family-based prevention and intervention program that integrates established clinical therapy, empirically supported principles, and extensive clinical experience. FFT is often used for youth ages 11 to 18 who are at risk for and/or presenting with delinquency, violence, substance use, conduct disorder, oppositional defiant disorder, or disruptive behavior disorders (Underwood & Washington, 2016). This model allows for intervention in complex problems through clinical practice that is flexibly structured, culturally sensitive, and accountable to families (Sexton & Alexander, as cited by the NCMHJJ, 2002).

FFT focuses on treating youth who exhibit delinquency and maladaptive "acting out" behaviors by seeking to reduce them by identifying obtainable changes (NMHA, 2004). A research study indicated that one year after treatment youth who participated in FFT had a re-arrest rate of approximately 25 percent (NMHA). This was significantly lower than the arrest rate (45 to 75 percent) for youth who had not received FFT (NMHA). Numerous FFT outcome studies have been published, with participants ranging in clinical severity from status offenders to youth presenting serious antisocial behavior. Most of these studies demonstrated favorable decreases in antisocial behavior for youth who participated in FFT (Henggeler & Schoenwald, 2011).

# Treatment Foster Care Oregon

Treatment Foster Care Oregon (TFCO) (formerly Multidimensional Treatment Foster Care) recruits, trains, and supervises foster families to provide youth with close supervision, fair and

consistent limits and consequences, and a supportive relationship with an adult (NCMHJJ, 2002). As an alternative to corrections, it places juvenile offenders who require residential treatment with these carefully trained foster families (American Academy of Child and Adolescent Psychiatry [AACAP], 2013). TFCO also provides individual and family therapy, educational programming, and psychiatric care. It is effective in reducing delinquent behaviors, justice system contacts, substance use, depression, and teen pregnancy and promotes both rehabilitation and public safety (Zajac, Sheidow, & Davis, 2015; Chamberlain, 1998). During the placement timeframe, the youth's biological or adoptive family also receives family therapy to further the goal of returning the youth to that family (NMHA, 2004).

Chamberlain (1998) found that TFCO was superior to traditional group care in short- and long-term outcomes among juvenile offenders. These outcomes included decreases in running away from home, higher rates of program completion, and decreases in the frequency of being locked up in a detention or training center. Research has shown that male juvenile offenders who participated in TFCO, as compared to traditional group care, were more likely to return home to reside with relatives and to have less official and self-reported criminality (e.g., violent crimes or delinquent behaviors) (Chamberlain & Reid, 1998).

# Family Centered Treatment

The information in the following paragraph is from the Institute for Family Centered Treatment (Sullivan, Bennear & Painter, 2009). A treatment approach that shows promise is family centered treatment (FCT). FCT was developed by the Institute for Family Centered Services (IFCS) as an intensive, in-home treatment. The goal of FCT is to keep youth in the community and divert them from further penetration into the juvenile justice system. FCT seeks to address the causes of parental system breakdown while integrating behavioral change. FCT is structured into four phases: joining and assessment, restructuring, value change, and generalization.

The FCT program performs at least as well as residential programs and at a substantially lower cost. One study found that, in the first year following treatment, 11 percent fewer youth were in secure detentions, 23 percent fewer youth were in residential placements, 16 percent fewer youth were pending placements, and there was a 30 percent reduction in length of residential placement. Additional research is needed to show the long-term effectiveness of FCT.

# Psychological Treatments

Psychological treatments provide guidance and support for juveniles with mental disorders (NCMHJJ, 2007). Treatments are conducted by appropriately trained and licensed mental health professionals. The type and length of treatment varies according to individual treatment plans (NCMJJ). Some examples of psychological treatments are discussed below.

# Cognitive Behavioral Therapy

Cognitive behavioral therapy (CBT) is a therapeutic approach that focuses on the relationship between thoughts, feelings, and behaviors in maladaptive outcomes. For example, CBT may focus on the idea that dysfunctional thoughts lead to maladaptive behaviors and feelings. This structured approach involves teaching youth about the relationship between their thoughts and their behaviors, and helps them employ more adaptive behaviors in challenging situations. This

approach is especially beneficial for youth in the juvenile justice system because it is very structured and focuses on the triggers for disruptive or aggressive behavior (NMHA, as cited by the NCMHJJ, 2002). CBT addresses poor interpersonal and problem-solving skills by teaching participants social skills, coping, anger management, self-control, and/or social responsibility (NMHA, 2004). A meta-analysis highlighted the effectiveness of CBT in treating convicted offenders, specifically highlighting the impact of CBT in reducing future delinquency and recidivism rates and displaying the positive effects of cognitive restructuring and skills (Underwood & Washington, 2016; Wilson, Bouffard, & MacKenzie, 2005). However, follow-up studies found that that without changing the contextual factors that instill and reinforce maladaptive social decision-making and provide opportunities for continued behavior problems (e.g., time with delinquent peers, school expulsion), disruptive behaviors may persist (McCart & Sheidow, 2016).

# <u>Dialectical Behavior Therapy</u>

Dialectical behavior therapy (DBT) was originally developed and validated for use with individuals with borderline personality disorder, but has since been adapted to treat juvenile offenders (Linehan et al., 1991). It consists of individual and group therapy components and focuses on validating the behaviors and feelings of the juvenile. It also focuses on the youth making positive changes, such as developing emotional regulation skills (Skowyra & Cocozza, 2006). DBT specifically aims to increase self-esteem and decrease self-injurious and other negative behaviors that interfere with therapy. Linehan and colleagues highlighted positive outcomes associated with DBT, including decreases in substance abuse, crisis situations, and suicidal ideation, and increases in treatment retention. One study adapted DBT for the treatment of incarcerated female juvenile offenders and found a significant decrease in problem behaviors in these females (Trupin et al., 2002).

# **Brief Strategic Family Therapy**

Brief strategic family therapy is a short-term, family-focused therapy that concentrates on changing family interactions and contextual factors that may lead to behavior problems in youth (U.S. Department of Health and Human Services, 2004). It includes three therapeutic techniques: developing a therapeutic alliance with family members, diagnosing the problem behavior(s), and restructuring or changing family interactions that lead to these problem behaviors. Brief strategic family therapy has been linked to decreases in substance abuse, reductions in negative attitudes and behaviors, and improvements in positive attitudes and behaviors (U.S. Department of Health and Human Services).

# Aggression Replacement Therapy

Aggression replacement therapy (ART) is a short-term, educational program that focuses on anger management and provides youth with the skills to decrease antisocial behaviors and to utilize prosocial behaviors. The three main components of ART are structured learning training (learning interpersonal and social skills), anger control training (learning how to deal with one's anger), and moral reasoning (learning how to develop mature moral reasoning) (Skowyra & Cocozza, 2006). Research has shown ART to be associated with productive interpersonal

interactions, improved problem-solving skills, and increased moral reasoning (Glick & Goldstein, 1987).

### Additional Treatment Considerations

Pharmacological treatments may be incorporated as a part of the juvenile's treatment plan when being utilized for a diagnosed mental health disorder. Evidence-based pharmacological treatments for various mental health disorders are discussed in greater detail in each of the *Collection*'s sections on specific disorders.

In addition to these specific treatment programs, researchers and policymakers have described some broader approaches or philosophies that are thought to produce positive outcomes for juvenile offenders. One such approach is the integrative systems of care (SOC) approach. The SOC approach typically involves collaboration across agencies, such as juvenile justice and mental health, with the goal of developing coordinated plans for family-centered services that build upon the strengths of youth and their families.

The Coalition for Juvenile Justice (2000) outlined nine components that are critical to effective treatment for juvenile offenders:

- 1. Highly structured, intensive programs focusing on changing specific behaviors;
- 2. Development of basic social skills;
- 3. Individual counseling that directly addresses behavior, attitudes, and perceptions;
- 4. Sensitivity to a youth's race, culture, gender, and sexual orientation;
- 5. Family member involvement in the treatment and rehabilitation of children;
- 6. Community-based, rather than institution-based treatment;
- 7. Services, support, and supervision that "wrap around" a child and family in an individualized way;
- 8. Recognition that youth think and feel differently than adults, especially under stress; and
- 9. Strong aftercare treatment.

# **Unproven Treatments**

Sukhodolsky and Ruchkin (2006) reviewed the treatments generally used for youth in the juvenile justice system and highlighted the limited application of evidence-based treatments to juvenile offenders. In short, although there may be ample evidence for treating youth with various psychopathologies, there is limited research on the implementation of these treatments in the juvenile justice system. This limitation highlights the need for more research to examine the effectiveness of these treatments among the juvenile offender population.

Research conducted with adult offenders who have mental health disorders revealed that interventions are effective during periods of confinement and that services should not be delayed (Morgan et al., 2012). Significant treatment gains can begin during confinement that can reduce the likelihood of recidivism and relapse. Ensuring continuity of care has been shown to reduce the rate of psychiatric hospitalizations and improve transition to the community. This is particularly important because the majority of juvenile offenders placed in confinement will eventually be released back to their communities.

### **Cultural Considerations**

The U.S. Surgeon General's Report on Culture, Race, and Ethnicity indicates a lack of research on culturally sensitive, evidence-based mental health assessments and treatments for minority youth in the juvenile justice system (2001). This report highlights the need for considering race and ethnicity in treatment outcomes, particularly because minority youth are overrepresented in the juvenile justice system (Snyder & Sickmund, 1999).

One study found that incarcerated African-American youth had the lowest rate of mental health diagnoses, non-Hispanic Caucasian youth had the highest rate, and the rate for Hispanic youth fell between these two groups (Teplin et al., 2002). Thus, white youth in the juvenile justice system may, on average, be more dysfunctional (have greater psychiatric morbidity) than minorities. However, as discussed in the research, interpreting and evaluating rates of mental health diagnoses within the juvenile justice system can be difficult among minority youth, particularly if these youth are reluctant to admit mental health concerns or if their families have a cultural bias against seeking care (American Academy of Pediatrics Committee on Adolescence, 2011).

In a study of abuse and psychological problems of children in juvenile detention centers, as many as two-thirds of males and three-quarters of females suffered at least some physical abuse prior to incarceration. The physical abuse was more likely to be severe in non-Hispanic Caucasian and Hispanic females than in African-American females, and non-Hispanic Caucasian males were more likely than Hispanic or African-American males to suffer several types of physical abuse (King, et al., 2011). Non-Hispanic Caucasian females were more likely to be sexually abused than Hispanic or African-American females (King, et al.).

Non-Hispanic Caucasian youth in juvenile detention are more likely to have comorbid mental health disorders. This is true in females and in males (Abram et al., 2003). Non-Hispanic Caucasian and Hispanic youth were also more likely than African American youth to have drug and alcohol abuse disorders (Abram et al.). Although minorities have lower rates of comorbidity, they comprise up to two-thirds of youth in the juvenile justice system and are more likely to require services to address their comorbid disorders than non-minority youth (Abram et al.).

# Services in Virginia

Each year, a significant number of juveniles with mental health problems enter Virginia's juvenile justice system. The Virginia Department of Juvenile Justice (VDJJ) assesses juveniles as they enter the system to ascertain their needs and what services are to be provided. Below is information about several Virginia-specific initiatives.

### Services in Juvenile Detention Facilities

The following information is from the Virginia Department of Behavioral Health and Developmental Services (K. Hunter, personal communication, October 16, 2017). Virginia's local community service boards (CSBs) provide mental health screening, assessment services, and community-based referrals for youth in local juvenile detention facilities. A CSB's primary role in a juvenile detention center is providing short-term mental health and substance abuse services to juveniles incarcerated in the center with mental illnesses or mental illnesses and co-

occurring substance use disorders. As part of this role, CSBs consult with juvenile detention center staff on the needs and treatment of juveniles. This may include case consultation with detention center staff. Since the juveniles have been court ordered to the center, they are under the jurisdiction of the center for care. CSBs provide consultation and behavioral health services in support of the centers care of juveniles. Target populations are those juveniles admitted to the designated detention center who are:

- Admitted to detention for a delinquent act;
- Determined to be in need of mental health services according to the MAYSI-II or by referral; and
- Not in need of immediate hospitalization.

Clinical services in juvenile detention are designed to provide short-term mental health and substance use services. A CSB may provide the following core services to juveniles served in juvenile detention centers:

- Emergency;
- Consumer monitoring;
- Assessment and evaluation; or
- Early intervention services.

# Child Psychiatry and Children's Crisis Response Services

In its 2011 report to the Virginia General Assembly, entitled "A Plan for Community-Based Children's Behavioral Health Services in Virginia" (Item 304.M.), the Virginia Department of Behavioral Health and Developmental Services (VDBHDS) outlined the comprehensive service array necessary to meet the needs of children with behavioral health problems (VDBHDS, 2017). The service array included crisis response services, which includes mobile crisis and crisis stabilization services. Rural CSBs were particularly challenged in supporting these service models, so a regional approach was proposed to allow the services to be shared among CSBs. Regions experienced the most growth in the number of children who were served by face-to-face psychiatric visits, tele-psychiatry, and psychiatric consultation with pediatricians and primary care physicians. Because the Commonwealth's general fund allocation for these services has increased from \$1.5 million in Fiscal Year 2013 to \$8.4 million in Fiscal Year 2017, there has been significant growth in the number of children who received mobile crisis and crisis stabilization services. Youth in detention centers are also receiving these services.

### Mental Health Services Transition Plans

The following is taken from the Virginia Department of Juvenile Justice (VDJJ) (2010). Developing a mental health transition plan helps with the transition of mental health services for juveniles committed to VDJJ. In 2005, the Virginia General Assembly enacted legislation requiring the planning and provision of mental health, substance abuse, or other therapeutic treatment services for juveniles who were returning to the community following commitment to a juvenile correctional center or post-dispositional detention. The intent of this requirement was to improve outcomes for juveniles committed to the Department through improved transition planning. The implementation date for these plans was January 2008. All juveniles committed to

VDJJ are to be evaluated, at intake, by a qualified mental health professional to determine if they qualify for a mental health services transition plan. Services for identified juveniles are secured prior to their release. For all identified youth, the assigned counselor must schedule a facility eligibility review meeting 90 days prior to the juvenile's release date. This meeting includes the juvenile's legal guardian, probation or parole officer, facility staff knowledgeable about the juvenile's mental health needs, and the juvenile.

### **Overview for Families**

The juvenile brain is not fully mature. For this reason, young people are less able to use good judgment and are more prone to influence from family, school, peers, and community. In addition, stress, peer pressure, and immediate reward are more likely to influence the behavior of youth than the behavior of adults.

Table 3 outlines factors that may make it more or less likely that youth will enter the juvenile justice system. No single risk or protective factor can predict whether a youth will become a juvenile offender. However, reducing risk factors and promoting protective factors may help keep youth out of the juvenile justice system.

Table 3
Factors Affecting Entrance Into the Juvenile Justice System

Risk Factors	Protective Factors
<ul> <li>Substance use</li> <li>Low grade point average</li> <li>Aggressive responses to shame</li> <li>Lack of involved adults in community</li> <li>Inadequate command of behaviors or high emotional distress</li> <li>Low IQ or learning difficulties</li> <li>Disengaged family</li> <li>Chronic school truancy</li> </ul>	<ul> <li>High self esteem</li> <li>High expectations</li> <li>Structure and rules at home</li> <li>Positive attitudes about school rules and law enforcement</li> <li>Access to adults with whom the child can discuss problems</li> <li>Involvement in learning</li> <li>Secure attachment to caregivers</li> <li>Sense of belonging</li> </ul>

Sources: CDC, 2017; Carr and Vandiver, 2001; Research & Training Center on Family Support and Children's Mental Health, 2001; Youth.gov, n.d.

Studies have shown that juvenile offenders are more likely to have mental health disorders. Treating these disorders may help youth overcome other causes of juvenile delinquency. Affected families are encouraged to reach out to community-based services for additional assistance.

# Conclusion

Community agencies, such as social services, public school divisions, and the juvenile justice system, frequently serve youth with untreated or under-treated mental health disorders. The juvenile justice system serves those youth whose behavior or actions bring them under the

purview of the court. Although juvenile offenders with mental health disorders are a challenging population, promising intervention strategies do exist. However, it is important to remember that, although the juvenile justice system should respond to the mental health needs of youth, the juvenile justice system cannot supplant the mental health system (Boesky, 2002). To effectively serve juvenile offenders with mental health treatment needs, there should be shared responsibility between the juvenile justice and mental health systems. Services should be gender responsive and should integrate recent advances in trauma-based care. They should also involve families as fully as possible in the treatment of their children (Skowyra & Cocozza, 2006).

# **Resources and Organizations**

American Academy of Child & Adolescent Psychiatry (AACAP)

https://www.aacap.org/

**National Center for Juvenile Justice (NCJJ)** 

http://www.ncjj.org/

**National Center for Mental Health and Juvenile Justice (NCMHJJ)** 

https://www.ncmhjj.com

**National Child Traumatic Stress Network** 

http://www.nctsnet.org/

**National Council of Juvenile and Family Court Judges** 

https://www.ncjfcj.org/

Office of Juvenile Justice and Delinquency Prevention (OJJDP)

https://www.ojjdp.gov

# **Virginia Resources and Organizations**

Virginia Department of Behavioral Health and Developmental Services (VDBDHDS)

http://www.dbhds.virginia.gov/

Virginia Department of Criminal Justice Services (VDCJS)

http://www.dcjs.virginia.gov/

Virginia Department of Juvenile Justice (VDJJ)

http://www.djj.virginia.gov/

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### JUVENILE FIRESETTING

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#### Introduction

When juvenile delinquency is mentioned, arson is not usually the first type of offense that comes to mind. However, between 2007 and 2011, the National Fire Protection Association (NFPA) reported that 282,600 intentional fires were reported to U.S. fire departments each year, with annual losses of 420 deaths, 1360 injuries, and \$1.3 billion in damaged property (Peters & Freeman, 2016). Moreover, 40 percent of individuals arrested for these events were less than 18 years of age (Peters & Freeman). Even more disturbing is that almost 85 percent of the victims of fires started by children are the children themselves, with 80 deaths and 860 injuries occurring annually (Campbell, 2014; Burn Institute, 2004). Although legal definitions of arson vary from state to state, a juvenile may be charged with arson when an evaluation of the event reveals sufficient evidence of malicious and willful firesetting (Office of Juvenile Justice and Delinquency Prevention [OJJDP], 1997).

Historically, juvenile firesetting has been viewed as a problem particular to "curious kids" (U.S. Fire Administration [USFA] of the Federal Emergency Management Agency [FEMA], 1997). Fires set by children playing with matches and lighters tend to be categorized as "accidental" or "child's play." However, juvenile firesetting includes the deliberate destruction of property by juveniles through fire, which sometimes results in casualties (USFA & FEMA). Researchers have attempted to characterize juvenile firesetters based on demographic, psychological, and psychiatric data. However, there is little consensus regarding specific risk factors or characteristics common to all juvenile firesetters because the factors are widely variable (Peters & Freeman, 2016). The evidence suggests that the cause for firesetting in juveniles is likely a complex interplay between environmental, psychological, and biological factors. The complex nature of juvenile firesetting necessitates an extensive intervention and a multidisciplinary array of services (Stadolnik, 2000).

#### **Causes and Risk Factors**

The general lack of consensus in medical, legal, sociological, and psychiatric fields on the topic of juvenile firesetting has contributed to the many myths about the disorder. Unfortunately, specific information is not available about the causes and risk factors of juvenile firesetting, as they are not definitively known. Most attention to firesetting has been included within broader categories of delinquency and aggression in children (MacKay et al., 2009). In the past two decades, professionals have attempted to conceptualize and develop theoretical underpinnings of juvenile firesetting behavior. However, firesetting is an elusive and complex behavioral problem. In order to explain firesetting, both individual and environmental predictors must be assessed simultaneously.

The concept of fire interest has consistently been associated with firesetting behavior in multiple studies and has been identified as a risk factor for recidivism (Peters & Freeman, 2016). In a study of 343 psychiatric patients, firesetters were distinguished from non-firesetters by the intensity of their curiosity about fire. In addition, early experiences with fire, early exposure to firesetting, and previous intentional firesetting behaviors are associated with juvenile firesetting behavior (Kolko & Kazdin, 1989).

Being male is frequently reported as a risk factor for firesetting (Peters & Freeman, 2016). One particular study of 43,000 adults showed a 1.7 percent lifetime prevalence rate of firesetting in men and 0.4% in women (Hoerte et al., 2011).

Substance use, specifically alcohol and cannabis, is another common risk factor identified in firesetting. One large study of 3,965 students in grades 7 to 12 revealed that binge drinking and frequent cannabis use to be associated with firesetting behavior, and youth who use additional illicit substances are more likely to be high-frequency firesetters (MacKay et al., 2009).

Researchers have also evaluated the role of maltreatment in firesetting behavior. One particular study of children aged 4 to 17 years reported that 48 percent of those who set fires experienced maltreatment and, compared with youth who had not experienced maltreatment, were more likely to have a history of firesetting and have more access to ignition sources (Root et al., 2008). This is consistent with reports that children with emotional and physical abuse are more likely to have a history of firesetting than children who did not experience abuse.

The adult literature has suggested an association between psychiatric illness and firesetting behavior, particularly with affective disorders and substance use disorders (Peters & Freeman, 2016). Children with firesetting behaviors were more likely than other juvenile offenders to have received mental health treatment and to have had suicidal thoughts in the past (Rasanen et al., 1995). Conduct disorder and attention-deficit/hyperactivity disorder (ADHD) have been associated with juvenile firesetting in some studies (Becker et al., 2004). Research also suggests that firesetting may be an attempt by the youth to regulate difficult cognitive, social, and/or emotional experiences (Tanner, Hasking, & Martin, 2015). These actions may serve to change the youth's current state of feelings by deliberately setting a fire, which in turn changes their current negative sensation. Firesetting can become a sensation-seeking practice for youth (Tanner, Hasking, & Martin). Other studies have shown that firesetting may be a way of dealing with the internalization of psychopathology (Tanner, Hasking, & Martin).

Researchers and clinicians are attempting to gather data about children who are firesetters and their families, the factors driving their behavior, and the number of firesetting incidents associated with the child—even if a fire department has never responded to any of the fires (Wilcox, 2000). Motivational typologies are often the most popular and simplest method by which practitioners and researchers attempt to understand juvenile firesetting (Stadolnik, 2000; Dittman, 2004). The various motivational typologies are listed in the following paragraphs.

<u>Curiosity-motivated firesetting</u> is "driven by a child's desire to learn or master fire through actual experimentation or play" (Stadolnik, 2000). Although some curiosity may be considered normative at certain developmental levels, extreme levels of curiosity are linked to later problematic firesetting behaviors. Recent empirical work has supported the importance of curiosity as an important factor (MacKay et al., 2006). Young children who play with fire often try to hide burned paper and lit matches (Dittman, 2004a).

<u>Crisis-motivated firesetting</u> describes a juvenile who feels "ineffective, anxious, and seemingly powerless in a world that they often experience as being out of their control" (Stadolnik, 2000). For these children, fire, as a powerful element, may offer a sense of mastery and competence. Depression, ADHD, or family stress may accompany this type of firesetting (Dittman, 2004b).

<u>Delinquent-motivated firesetting</u> conceptualizes the use of fire as one way of acting out against authority. These children rarely show empathy but tend to avoid harming others (Dittman, 2004a). Given that firesetting is one of 15 symptoms for conduct disorder, it makes sense to explore the relationship between delinquency and firesetting.

<u>Pathological-motivated firesetting</u> is the rarest of the motivations seen by practitioners in this field and describes a severely disturbed juvenile. It includes those who are actively psychotic, acutely paranoid or delusional, or who have lived in chronically disturbed and bizarre environments. A small, rare subtype of this group may meet criteria for pyromania (i.e., a pattern of deliberate firesetting for the pleasure/satisfaction derived from the relief of tension experienced before the fire-setting).

While motivational typologies can be useful in assessment and treatment interventions, many youth present with seemingly complex and multiple motivations for firesetting behavior. This limits a practitioner's ability to assign him or her within the current simplified models. Variables linked to juvenile firesetting include peer pressure, curiosity, mental health and substance abuse problems, and lack of adult supervision (Burn Institute, 2004; MacKay et al., 2009). Research has also found a relationship between involvement in firesetting and parents/caregivers who smoke, due to the availability of matches and cigarette lighters and because the purposive use of fire is familiar to the juvenile (Porth & Hughes, 2000).

#### Comorbidity

Clinical studies that have examined juvenile firesetters found that many have conduct and aggression problems. One study that researched conduct disorders (CD) and firesetting found that approximately 30 percent of youth participating in firesetting have been diagnosed with CD (Becker et al., 2004). Kolko (2002) found that early childhood firesetters often exhibit multiple

behavioral problems and externalizing behaviors, such as rule-breaking, aggression, destruction, and ADHD.

Approximately 15 percent of firesetting youth are females (MatchBook Journal, 2016). A study investigating the prevalence of self-reported firesetting determined that female firesetters are more likely to have serious antisocial behaviors, participate in risk-taking activities, and have a substance abuse problem (Becker et al., 2004; Martin et al., 2004). Another study, which researched a potential link between juvenile firesetting and delinquency, found that firesetters are more likely than non-firesetters to be delinquent, while adolescents who continue in the practice of firesetting tend to be chronically criminal (Becker et al.). Another significant finding is that firesetting may be related to extreme antisocial behavior that is not always accounted for by the presence of CD (Becker et al.). Finally, a relatively recent study by MacKay et al. (2009) demonstrated a clear link between firesetting and mental health and substance use, and suggested that a history of firesetting was associated with psychopathology during adolescence.

#### Assessment

Overall, individual and family-related factors that may predispose the firesetting youth should be identified in order to effectively treat this behavior. Assessing personality structure and individual characteristics, family and social circumstances, and immediate environmental conditions allow for more effective treatment (Williams & Clements, 2007). Factors to be considered include history or frequency of incidents, method, motive, ignition, target, and behavior (Sharp et al., 2005). It is important to gather data not only to plan treatment, but also to discover the motivation behind the firesetting behavior (Sharp, Blaakman, & Cole).

As outlined by Stadolinik (2000), several domains are crucial to a comprehensive evaluation of firesetting behavior and the development of a risk factor model for assessing this behavior:

- Fire incident;
- Fire history;
- Motives and precipitants;
- Consequences/family discipline;
- Developmental level/IQ;
- Psychiatric disorders and history;
- Family environment;
- The child's cognitive behavior repertoire;
- Parent functioning and practices;
- Social supports;
- Service availability; and
- Treatment outcome.

Assessment of a juvenile firesetters should include a comprehensive structured interview with the young person and their parents, with a view to getting information on family function, supervision, and discipline practices (Dolan et al., 2011). A number of firesetting assessment models, specific instruments, and protocols have been developed and are currently utilized by practitioners and researchers in the field. These tools are summarized in Table 1.

Table 1
Suggested Screening and Assessment Tools for Juvenile Firesetting

Name of Measure	Measure Type	Who Completes	Generated Information
Children's Firesetting Inventory (CFI)	Semi-Structured Interview	Clinician/Youth	Six dimensions related to firesetting behavior
Firesetting Risk Inventory (FRI)	Semi-Structured Interview	Clinician/Parents	Personal, familial, and social dimensions related to firesetting
F.I.R.E Protocol	Semi-Structured Interview	Clinician/Parents and Youth	Assessment of threat; risk of recidivism; specific treatment needs
Juvenile Firesetter Needs Assessment Protocol (JFNAP)	Semi-structured Interview	Clinician/Parents and Youth	Mental health needs; firesetter typology
Firesetting Incident Analysis (FIA-C) Child and Parent forms	Structured and Semi-Structured Interview	Clinician/Parents	General and fire-specific variables (e.g., firesetting motives, response to fires)
Firesetters Analysis Worksheet	Semi-Structured Interview	Clinician	Risk level/risk of recidivism
Firesetting History Screen (FHS)	Structured Interview	Clinician/Parents and Youth	Evidence of firesetting activities

Supplementary signals that clinicians may look for include the following:

- An appearance or lack of remorse may signal emotional issues when remorse is not present;
- Impulse control, frequent anger, and poorly managed emotions; and
- Frequency of firesetting (Community Health Strategies, 2015).

#### **Treatments**

Currently, there are no evidence-based treatment approaches for the juvenile firesetting population (Kolko, Herschell, & Scharf, 2006). However, the Office of Juvenile Justice and Delinquency Prevention identified seven components common to juvenile firesetting programs as successful (1997):

- 1. A program management component to make key decisions, coordinate interagency efforts and foster interagency support;
- 2. A screening and evaluation component to identify and evaluate children who have been involved in firesetting;

- 3. An intervention services component to provide primary prevention, early intervention, and/or treatment for juveniles, especially those who have already set fires or shown an unusual interest in fire;
- 4. A referral component to link the program with agencies that might help identify juvenile firesetters or provide services to them and their families;
- 5. A publicity and outreach component to raise public awareness of the program and encourage early identification of juvenile firesetters;
- 6. A monitoring component to track the program's identification and treatment of juvenile firesetters; and
- 7. A juvenile justice system component to forge relationships with juvenile justice agencies that often handle juvenile firesetters.

Additional treatment components that have been suggested in the literature are fire service collaboration and fire safety education, behavioral interventions, family therapy, and hospitalizations, residential placement, and/or medication (Stadolnik, 2000). Unfortunately, there is no single identified treatment that is considered effective for treating this behavior. However, many treatments have proven beneficial in the management of this behavior. These treatments are appropriately applied to firesetters with consideration for their age (Slavkin, 2000) and are outlined in Table 2.

#### Cognitive Behavioral Therapy, Fire Safety Education, and Firefighter Home Visits

Cognitive Behavioral Therapy (CBT) and Fire Safety Education (FSE) were found to significantly curtail firesetting and match play behaviors up to a year after intervention (Kolko, 2001). Firefighter Home Visits (FHV) have also been shown to significantly decrease the likelihood of juvenile firesetting (Kolko, Herschell, & Scharf, 2006). However, structured treatments designed to intervene with children who set fires were still found to have greater effect in the long-term than brief visits with a firefighter (Kolko). Both CBT and FSE were also shown to be effective at reducing other activities associated with firesetting, such as playing with matches and being seen with matches or lighters (Kolko).

Regardless of the seriousness of an incident or the child's motive in starting a fire, education regarding fire should be part of the intervention strategy. Education should include information about the nature of fire, how rapidly it spreads, and its potential for destructiveness (USFA, 1997; Campbell, 2014). Information about how to maintain a fire-safe environment, utilize escape plans and practice, and use fire appropriately has been shown to be an effective component of comprehensive arson intervention programs, at least for younger youth (USFA).

Social skills training may also help juveniles who have trouble expressing their emotions. These skills include asking for help, making friends, solving problems, responding to failure, answering complaints, expressing affection, and negotiating (Cole et al., 2006).

Table 2
Summary of Treatments for Juvenile Firesetting

What Works		
There are no evidence-based practices at this time.		
What Seems to Work		
Cognitive behavioral therapy (CBT)	Structured treatments designed to intervene with children who set fires. Because firesetting is a maladaptive behavior, CBT is a reasonable intervention to consider for behavior modification.	
Fire safety education (FSE)	Education includes information about the nature of fire, how rapidly it spreads, and its potential for destructiveness, as well as information about how to maintain a fire-safe environment, utilizing escape plans and practice, and the appropriate use of fire.	
Firefighter home visit (FHV)	Firefighters visit homes and explain the dangers of playing with fire to at-risk juveniles.	
What Does Not Work		
Ignoring the problem	Leaving youth untreated is not beneficial because they typically do not outgrow this behavior and ignoring these behaviors may increase dysfunctional behavior patterns.	
Satiation	Satiation, the practice of repetitively lighting and extinguishing fire, may cause the youth to feel more competent around fire and may actually increase the behavior.	
Burning the juvenile	Burning a juvenile to show the destructive force of fire is illegal/abusive. It will not decrease the likelihood of the juvenile setting fires or actually treat the problem.	
Scaring the juvenile	Scare tactics may produce the emotions or stimulate the actions the clinician is trying to prevent, particularly when family or social issues may trigger firesetting. Scare tactics may also trigger defiance, avoidance, or may even increase the likelihood that firesetting traits continue.	

Sources: Kolko, 2001; USFA, 1997; OJJDP, 1997; Stadolnik, 2000; Slavkin, 2000; Kolko, Herschell, & Scharf, 2006; Cole et al., 2006; FEMA, 2011; Peters & Freeman, 2016.

#### **Treatment Settings**

Sometimes it is determined that the juvenile should be confined to a secure facility, residential treatment center, or hospital, although treatment for firesetting usually occurs in the least restrictive environment, depending on the seriousness of the offense and on the needs of the child (USFA, 1997). Although many juvenile firesetters can be maintained in the community with appropriate supervision, careful assessment is crucial in order to provide the appropriate level of care (USFA). Such an assessment must consider the child, family, environment, facts about the fire and fire history, including the child's reaction to the fire and sense of accountability (USFA). Furthermore, consideration should be given to ensuring that the child does not pose a risk to others and public safety is protected.

#### Residential Facility

Many programs will not admit a child with a history of firesetting for fear the child will set a fire in the facility (USFA, 1997). However, residential treatment can provide a safe and comprehensive setting for treatment to firesetters, as well as treatment for any co-occurring or familial issues.

#### Foster Care

There is a strong link between neglect and abuse and firesetting, so placing a child in a safe, supervised family setting can be very effective in situations where there are unsubstantiated findings of abuse and neglect. When firesetting occurs as a result of neglect or abuse, the removal of the outside stressors can often cause the firesetting behavior to cease (USFA, 1997). Certain foster homes can be classified as "intensive" foster homes to allow for these difficult types of placements (USFA). Considerable attention is placed on fire safety practices and the foster parents receive in-depth training in working with difficult adolescents. Such training includes communication and problem-solving skills, supervision, behavior management, and fire safety education for prevention and intervention (USFA). Children in foster care receive counseling and additional support services, and the firesetter's parents are included as a component in the treatment plan (USFA). It is very important that the risk be acknowledged in this and any other community-based treatment intervention. Emphasis is placed on training and making the firesetter aware of the potential dangers of firesetting (USFA).

#### **Inpatient Hospitalization**

Although inpatient facilities may also be reluctant to accept children with a history of firesetting, inpatient treatment may be effective if an effective treatment protocol is in place (USFA, 1997). For example, Kolko (2002) has reported success using CBT to treat firesetting in an inpatient setting.

#### **Unproven and Contraindicated Treatments**

It is important to understand that leaving the child untreated is not beneficial because firesetters typically do not outgrow this behavior (Waupaca Area Fire District, 2002). Ignoring firesetting is unwise because it communicates disinterest in the child's well-being and experiences, which is likely to escalate dysfunctional behavior patterns (Sharp et al., 2005). Moreover, the problems must be addressed to prevent future fires.

Satiation, the practice of repetitively lighting and extinguishing fire, was once thought to be a deterrent to firesetting, based on the idea that a child curious about fire will tire of the exposure. However, the more practice a child has with fire, the more competent he or she may become, which may make the child more likely to increase the behavior (Sharp et al., 2005). Satiation, therefore, should not be used with firesetters.

Attempts at scaring a child from setting new fires by allowing one fire to get out of control is also not an appropriate treatment. This may trigger the emotions or stimulate the actions the clinician is trying to prevent, and this is more likely true in instances when family or social issues may trigger firesetting (Cole et al., 2009). Scare tactics may also trigger defiance or avoidance,

or may even increase the likelihood that firesetting traits continue (Cole et al.). Burning a juvenile on the hand is also not an acceptable deterrent for firesetters. It is illegal and abusive and should, under no circumstances, ever be used as a means to stop a child from setting fires (FEMA, 2011).

There are no medications indicated for the treatment of firesetting behaviors. Providers should consider firesetting behavior as a component of another psychiatric disorder until proven otherwise (Peters & Freeman, 2016). Diagnoses to consider include the disruptive behaviors as well as mood, anxious, and psychotic disorders. Substance use is also over-represented in the adolescent population of firesetters (Peters & Freeman). Identifying and treating a comorbid psychiatric condition may alleviate the firesetting behaviors.

#### **Overview for Families**

Families can prevent firesetting by following a few rules, such as the following from the U.S. Fire Administration (2012):

1. Teach children that matches and lighters are not toys.

About half of fires started by children are caused by children playing with matches and lighters.

Children set fires for a variety of reasons, including curiosity about fire, crying for help, or engaging in delinquent behavior.

- 2. Never allow children to play with lighters or matches.
- 3. Keep all matches and lighters out of the reach of children.

Store in a high cabinet, preferably locked.

- 4. Do not leave young children unattended.
- 5. Teach young children to tell a grown-up when they see matches or lighters.

Praise children when they tell you about found matches and lighters.

6. If a child is overly interested in fire, has played with matches and lighters, or has started a fire, the family must address this natural curiosity immediately and teach the child about the dangers of fire.

In this event, call your local fire department and ask if they have a juvenile firesetters intervention program.

Some of the reasons youth set fires include the following reason outlined in Table 3.

Table 3
Reasons for Juvenile Firesetting

Reasons for Firesetting	Description
Curiosity	A child sets a fire to learn more about fires and how they can be set
Crisis motivated	A child sets a fire because they feel they have lost power. The fire gives them a false sense of mastery
Delinquent firesetting	A child sets a fire to rebel against authority
Pathological firesetting	A severely disturbed youth may set fires because of a severe mental disorder
Cognitive impairment	A cognitively-impaired child may set a fire because they lack good judgment
Sociocultural firesetting	A child sets a fire because of peer pressure, external pressures, or religious motives

Sources: Dittman, 2004b; Porth & Hughes, 2000.

If a school-age child intentionally sets fires, even after being appropriately punished, families must consider getting professional help. Intervention is even more important if the child is setting fires to larger items or in instances where the flames can easily spread, causing injury and damage (Kids Health, 2014).

#### Conclusion

Current theories suggest that juvenile firesetting behaviors appear to stem from a complex interplay of individual and environmental factors. Given their unique circumstances and characteristics, individual firesetters require extensive evaluation to determine the best course of treatment. An appropriate review of firesetting should include an examination of the firesetter's history, such as prior fire learning experiences, cognitive and behavioral reviews, and parent and family influences and stressors (Slavkin, 2000).

#### **Resources and Organizations**

#### Federal Emergency Management Agency (FEMA)

U.S. Fire Administration

https://www.usfa.fema.gov/

#### Office of Juvenile Justice and Delinquency Prevention (OJJDP)

https://www.ncjrs.gov/

#### **Virginia Department of Fire Programs (VDFP)**

https://www.vafire.com/

#### **Youth Firesetting Information Repository & Evaluation System (YFIRES)**

https://yfires.com/

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# Sexual Offending

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#### Introduction

Juvenile sexual offenders are defined as youth who commit any sexual interaction with persons of any age against their will, consent, or in an aggressive, exploitative, or threatening manner (Finklehor, Ormrod, & Chaffin, 2009; Scavo & Buchanan, as cited by Ryan, Hunter, & Murrie, 2014). While the majority of juvenile sexual offenders are between puberty and the age of legal majority, a small number of juvenile offenders are younger than 12 years of age (Finklehor, Ormrod, & Chaffin). Sexually abusive behaviors can vary from non-contact offenses to contact offenses. A contact offense requires unwanted physical contact with a victim. With a non-contact offense, the perpetrator has no physical contact with the victim (e.g., Internet crimes) (Office of Juvenile Justice and Delinquency Prevention [OJJDP], 2001). Juvenile sexual offenders' behaviors have the potential to cause significant harm to others and also have significant legal ramifications (O'Reilly & Dowling, 2008). It is important to note that it is not until the youth has been found guilty or adjudicated in a court of law that the term "juvenile sexual offender" is technically accurate. However, the term "juvenile sexual offender" will be utilized in this section since much of the research on youth who engage in sexually abusive behavior utilizes this term.

Juvenile sexual offending is a serious problem that has increasingly become a focus of attention and concern (Finklehor, Ormrod, & Chaffin, 2009). A 2009 research brief from the U.S. Department of Justice notes that juveniles account for more than one-third (35.6 percent) of those who have committed sex offenses against minors and comprise more than one-quarter (25.8 percent) of all sexual offenders (Fonagy et al., 2015; Finkelhor, Ormrod, & Chaffin).

Research also suggests that the proportion of juvenile offenders increases as the age of the victim decreases (Fonagy et al.). Approximately half of all adult sexual offenders began their criminal offenses during adolescence (Chu & Thomas, 2010; Saleh & Vincent, 2004). In Virginia during Fiscal Year 2016, 14 percent of the admissions to the Virginia Department of Juvenile Justice (VDJJ) were for sexual abuse offenses, with the sexual abuse offense being the most serious committing offense (VDJJ, 2016).

Juvenile sexual offenders are fundamentally different from adults in their cognitive capabilities and their ability to regulate emotions and control behavior. Juveniles also have less capacity than adults in weighing the consequences of their actions. Research demonstrates the regions of the brain associated with foresight and planning continue to develop well beyond adolescence (U.S. Department of Justice Office of Sex Offender Sentencing, Monitoring, Apprehending, Registering, and Tracking [SMART], 2014). These factors must be acknowledged in the assessment and treatment of juvenile sexual offenders.

#### **Etiology and Characteristics of Juvenile Sexual Offenders**

The research on etiological factors for sexual offending includes studies that focus on single factors as well those that focus on multiple factors. There is consensus that etiological factors typically vary in the development and onset of sexual offending and nonsexual delinquency adolescence (U.S. Department of Justice, Office of SMART, 2014). These factors will be highlighted in the paragraphs that follow.

Sexual and physical abuse, child neglect, and exposure to family/domestic violence are all factors associated with juvenile sexual offending (Finklehor, Ormrod, & Chaffin, 2009; Center for Sex Offender Management, 1999). There is strong evidence that indicates that sexual victimization in childhood plays a role in the development of sexually abusive behavior in adolescents (Jesperson, Lalumiere, & Seto, 2009). Grabell and Knight (2009) examined child sexual abuse patterns and sensitive periods in the lives of juveniles who had committed sexual offenses. They found that children between ages three and seven are at an age when sexual abuse can do the most damage and place youth at higher risk for engaging in sexually abusive behavior later in life. This study found that both the ages of the victims and the length of the sexual abuse are significant factors that contribute to attitudes and behaviors in juveniles who commit sexual offenses.

Research has also shown that there are two types of juvenile sexual offenders: those who target children, and those who offend against their peers or against adults (Hunter, 2000). Moreover, there are also differences in motivation. Some offenders have histories of violating the rights of others; some are sexually curious; and some have serious mental health issues or poor impulse control (Finklehor, Ormrod, & Chaffin, 2009).

In general, 90 percent of all juvenile sexual offenders are male. Of that number, a significant portion of juvenile male sexual offenders ages 12 to 14 years target four- to seven-year-old boys (Finklehor, Ormrod, & Chaffin, 2009). By contrast, older offenders tend to abuse older female victims, peaking with 15 to 17 year olds targeting 13- to 15-year-old girls. This suggests that teen offenders targeting boys seek younger, sexually immature boys rather than peers, and older teen

offenders target sexually mature females (Finklehor, Ormrod, & Chaffin). Figure 1 outlines the characteristics of sexually abusive juveniles.

#### Figure 1

#### **Characteristics of Sexually Abusive Juveniles**

- Perpetrators are typically adolescents, age 12 to 17.
- Perpetrators are predominantly male.
- Perpetrators have difficulties with impulse control and judgment.
- Up to 80 percent of perpetrators have a diagnosable psychiatric disorder.
- Between 30 to 60 percent of perpetrators exhibit learning disabilities and academic dysfunction.

Sources: Center for Sex Offender Management, 1999; Hunter, 2000; Finklehor, Ormrod, & Chaffin, 2009.

Research has provided several promising leads to understanding the juvenile sexual offender. A significant proportion of juvenile sexual offenders may present with a diverse range of disordered behaviors, such as aggressive behavior, bullying, vandalism, firesetting, cruelty to animals, shoplifting, and drug/alcohol abuse. Furthermore, although rates of sexual re-offending are generally low-to-moderate for juvenile sexual offenders overall (8 to 15 percent), evidence suggests that youth who have offended sexually and who are highly antisocial have an extremely high risk of re-offending when criminal profiles include non-sexual charges (46 to 54 percent) (Lobanov-Rostovsky, 2015; O'Reilly & Carr, 2006; Worling & Langstrom, 2006).

Juvenile sexual offenders differ from their adult counterparts in that juveniles typically do not present with the same types of sexual deviancy and psychopathic tendencies that may be observed among adult offenders (Saunders, Berliner, & Hanson, 2001). However, there is evidence that juvenile sexual offenders who evade detection and/or treatment may be at higher risk of continued re-offending (Trivits & Reppucci, 2002).

#### Female Juvenile Sexual Offenders

There are few studies that address female juvenile sexual offenders. Due to the difficulty in finding adequate samples of female participants, female sexual offending has been underreported and under-represented in sexual offender literature (National Center on Sexual Behavior of Youth [NCSBY], 2004).

Although these studies have limitations, they have been pertinent in identifying implications for treating female juvenile sexual offenders (National Center on Sexual Behavior of Youth [NCSBY], 2004). Preliminary research has revealed that these females had very disruptive and tumultuous childhoods, with high levels of trauma and exposure to dysfunction with post-traumatic stress disorder (PTSD) being especially prevalent (Hunter, Becker, & Lexier, 1997). Compared to those of juvenile males, the histories of females in these studies reflected even more extensive and pervasive childhood maltreatment because many of these females were

exposed to interpersonal aggression by both females and males (Mathews, Hunter, & Vuz; NCSBY). Physical abuse is present in 20 percent of studied cases and sexual abuse is present in 50 percent of studied cases (Mathews, Hunter, & Vuz; NCSBY). Moreover, these females' histories revealed that they were victimized at younger ages and were more likely to have had multiple perpetrators (Mathews, Hunter, & Vuz; NCSBY). In samples of prepubescent female sexual offenders, rates of sexual victimization tend to be extraordinarily high, with rates greater than 90 percent (Hunter, Becker, & Lexier, 2006). High levels of impulsive delinquent behaviors, including substance abuse and other high-risk behaviors, were also observed (Mathews, Hunter, & Vuz).

Studies are being conducted to ascertain effective assessment and treatment measures for female juvenile sexual offenders. Tools used to assess female juvenile sexual offenders are lacking since they have been validated only on male offenders and have not yet been empirically validated with a female population (Center for Sex Offender Management [CSOM], 2007). Furthermore, most treatments are primarily tested on adult subjects and have less external validity with the youth population (Ryan, Hunter, & Murrie, 2014). Traditional psychological evaluation (e.g., intellectual and personality assessment) may be of more value with female juveniles until future tools are empirically validated with this population (Hunter, Becker, & Lexier, 2006). Preliminary results indicate that treatment approaches should be used to address the early and repetitive developmental traumas experienced by these offenders. Furthermore, female juvenile sexual offenders may benefit from a focus on the unique considerations of gender issues, including sexual and physical development, intimacy and social skills, self-image, self-esteem, impulsivity, comorbid symptoms of PTSD, and the common societal expectation of females as caregivers/nurturers (Roe-Sepowitz & Krysik, 2008).

#### Comorbidity

There have been studies conducted to ascertain the co-occurrence of mental health disorders in juvenile sexual offenders; however, many of these studies are limited (Ryan, Hunter, & Murrie, 2014; Boonmann et al., 2016a). The studies conducted to date have found that juvenile sexual offenders may share some characteristics other than sexual offending, including:

- High rates of learning disabilities and academic dysfunction;
- Attention-deficit/hyperactivity disorder (ADHD);
- The presence of other behavioral problems and conduct disorder; and
- Difficulties with impulse control and judgment (Saleh & Vincent, 2004).

One study found that three quarters of juveniles who sexually offended met criteria for at least one mental health disorder ('t Hart-Kerkhoffs et al., 2015). Juvenile sexual offenders with prepubescent child victims showed higher rates of internalizing and affective disorders (e.g., depression, bipolar disorder, and anxiety disorder) with 63 percent having one of these diagnoses. Of juvenile sexual offenders with prepubescent child victims, 58 percent had an ADHD diagnosis, 53 percent had a disruptive behavior disorder diagnosis (e.g., conduct disorder and oppositional defiant disorder), and 21 percent had a substance use disorder ('t Hart-Kerkhoffs et al.).

A recent study comparing mental health concerns of young male offenders with and without sex offenses found that those with a history of sexual offending were more likely to report internalizing mental health problems such as suicidal ideation and thought disturbance. Those with externalizing mental health problems were more likely to have anger-irritability problems (Boonmann et al., 2016b). This study also noted a relationship between these symptoms and childhood abuse or neglect, especially sexual abuse, when compared to youth with similar symptoms who did not have histories of sexual offending. This study concluded that because internalizing mental health disorders are harder to detect than externalizing mental health problems, it is of great importance to assess juvenile sexual offenders for both internalizing and externalizing mental health disorders. Because there is evidence that the relationship between sexual abuse and sexual offending behavior could be caused indirectly through mental health disorders, one aspect of sexual violence risk management among juveniles who have experienced sexual abuse could include treatment with a focus on healthy development and behaviors (Boonmann et al.).

Adolescent female sexual offenders also report high levels of childhood physical abuse and exposure to domestic violence (Ryan, Hunter, & Murrie, 2014). As noted previously, PTSD is a frequent comorbid condition in juvenile females who engage in sexually abusive behavior, particularly those found in residential treatment centers (Ryan, Hunter, & Murrie). PTSD may lend itself to mood regulatory and impulse control problems (Hunter, Becker, & Lexier, as cited by Ryan, Hunter, & Murrie). Mood disturbances, histories of substance abuse, and problems of conduct are also closely associated with extensive trauma histories and are frequently found in female sexual offenders as well (Hickey et al., as cited by Ryan, Hunter, & Murrie).

Ignoring comorbid mental health disorders may compromise the efficacy of structured sex offender treatment (Ryan, Hunter, & Murrie, 2014). Treatment for the comorbid mental health disorder may sometimes be provided simultaneously with other forms of sexual offender treatment. However, if the juvenile offender is psychotic, manic, or severely depressed, treatment in an inpatient setting may be necessary.

#### **Assessment**

Once a juvenile sexual offender has been identified, careful assessment is critical so that his or her needs can be matched to the correct type and level of treatment. Ideally, the assessment will indicate the level of danger that the juvenile presents to the community, the severity of psychiatric and psychosexual problems, and the juvenile's amenability to treatment. All available participants should be included in the assessment process, including the youth, his or her parents or guardians, and all other professionals involved, such as teachers, case workers, social workers, and mental health treatment providers (O'Reilly & Dowling, 2008). During the assessment process, it should be expected that the youth and his or her family may be at various psychological stages, ranging from complete denial to full acknowledgment of the sexual offense(s). For this reason, it may be helpful to consider full acknowledgment of offending behavior as a goal of treatment (O'Reilly & Dowling).

The information in this section is taken from research compiled by the Center for Sex Offender Management (1999). Professional evaluation of juveniles and their appropriateness for placement should be conducted post-adjudication and prior to court sentencing. Clinical

assessments should be comprehensive and include careful record reviews, clinical interviewing, and screening for co-occurring mental health disorders.

The primary purpose of the assessment is to ascertain the risk of future sexual offending so that the most effective steps can be taken to reduce, contain, or eliminate risk (Rich, 2014). Hence, risk assessment essentially serves as an investigative tool that helps inform and guide various intervention, treatment, and legal processes. Most studies designed to assess the accuracy and validity of juvenile risk assessment instruments have focused on the overall structure and predictive accuracy of the most widely used instruments rather than on the individual risk factors within them. Since many of the risk factors used in these instruments have not been empirically validated, studies have produced inconsistent results (Rich). However, there is some empirical support for the capacity of risk assessment instruments to identify statistically valid risk factors as well as for the predictive validity of various instruments (Rich). Table 1 provides a listing of available assessment instruments currently available for juvenile sexual offenders.

Table 1
Assessment Tools for Juvenile Sexual Offenders

Assessment Tool	Description	
Juvenile Sex Offender Assessment Protocol-II (J-SOAP-II)	Can be used either in a clinical or non-clinical setting. Assesses short term risk in juveniles between the ages of 12 and 18	
Estimate of Risk of Adolescent Sexual Offence Recidivism (ERASOR)	Clinical assessment used to identify short term risk in juveniles between the ages of 12 and 18	
Juvenile Sexual Offence Recidivism Risk Assessment Tool-II (J-SORRAT)	Actuarial assessment tool used to determine recidivism likelihood in convicted sexual offenders between ages 12 and 18	
Juvenile Risk Assessment Scale (JRAS)	Clinical assessment used to determine the risk of a youth between the ages of 12 and 18	
Structured Assessment of Violent Risk in Youth (SAVRY)	Not a formal judgment. Used in Collaboration with other clinical techniques to assess juvenile risk factors	
Hare Psychopathy Checklist: Youth Version (PCL:YV)	Clinical interview used to assess possible negative behavioral patterns	

Source: Center for Sexual Offender Management, 2007.

Studies conducted on the predictive accuracy of well-known risk assessment instruments showed differences in the predictive accuracies for general, violent, and sexual recidivism, and none of the instruments showed indisputable positive results in predicting future offending (Hempel et al., 2013). The two assessment tools with moderate predictive success are the Juvenile Sex

Offender Assessment Protocol-II (J-SOAP-II) and Estimate of Risk of Adolescent Sexual Offense Recidivism (ERASOR) (Hempel et al., 2013; Worling, Bookalam, & Litteljohn, 2012). ERASOR is also most effective in assessing non-Western offenders (Chu et al., 2012). One study asserted that other ways of assessing sexual risk should be developed, and because juveniles are rapidly developing, there is a need for reliable measures concerning short-term risk (Hempel et al.).

#### Assessment of the Juvenile's Home

Assessments of the juvenile's appropriateness for community-based programming should include a thorough review of his or her living arrangements, as well as a determination of whether the parents are capable of providing supervision (Center for Sex Offender Management, 1999). Decisions about whether an adolescent sexual offender should remain in the same home as the victim of his or her offense should be made carefully on a case-by-case basis. The decision may involve input from a variety of professionals (e.g., child protection workers, therapists, etc.). It is essential that the community and other children be protected from potential harm, both physical and psychological.

#### **Treatments**

Ethical issues have made it difficult to conduct controlled outcome studies on the treatment of juvenile sexual offenders. However, a number of encouraging clinical reports have been published with suggested treatment guidelines (Burton, Smith-Darden, & Frankel, 2006). Research has demonstrated that the overall prognosis for children with sexual behavior problems is good and that sexually abusive juveniles benefit from treatment (Farniff & Becker, 2006).

Promising sexual offender treatment programs often combine an intensive, multi-modal approach with early intervention. Comprehensive treatment may focus on taking responsibility for one's sexual behavior, developing victim empathy, and developing skills to prevent future offending. While juveniles are responsible for a significant portion of sexual offending, research on effective therapeutic interventions remain somewhat limited.

#### **Recommended Components**

A survey of professionals working with juvenile sexual offenders led to the identification of what may be considered recommended treatment components. Nominated components included anger management; correcting cognitive distortions about sexuality and relationships; fostering prosocial emotional, cognitive, and behavioral skills; and providing education about the offense cycle and pathways to sexual offending behavior (O'Reilly & Dowling, 2008). Parents or guardians need to be involved in the assessment and treatment process (Schladale, 2002). A summary of the recommended components of intervention programs for juvenile sexual offenders is provided in Table 2.

Table 2

Recommended Components of Intervention Programs for Sexually Offending Youth
As Endorsed by Mental Health Professionals

Treatment Component	Percent of Mental Health Professionals Endorsing
Essential	
Development of emotional competence skills, including the management of anger and distress	93
Changing cognitive distortions about sexuality and relationships	90
Development of prosocial emotional, cognitive, and behavioral skills	87
Gaining an understanding of his/her offense cycle and/or pathways into sexually abusive behaviors	85
Sexuality education	85
Life space work (understanding boundaries and social interaction and the development of social skills)	84
Development of relapse prevention skills	84
Working with the family	82
Understanding the consequences of further abusive behavior	81
Development of empathy	81
Desirable	
Dealing with deviant sexual urges	79
Problem solving	71
Additional	
Promoting appropriate positive sexual thoughts, while changing sexually abusive thoughts	63

Source: O'Reilly & Dowling, 2008.

#### **Promising Treatment Approaches**

The following paragraphs discuss two promising treatment approaches: multisystemic therapy for problem sexual behaviors (MST-PSB) and cognitive behavioral therapy (CBT). Table 3 outlines treatments for sexually offending youth.

Table 3
Summary of Treatments for Sexually Offending Youth

What Works				
There are no evidence-based practices at this time.				
What Seems to Work				
Multisystemic therapy for problem sexual behaviors (MST-PSB)	An intensive family- and community-based treatment that addresses the multiple factors of serious antisocial behavior in juvenile sexual abusers			
Cognitive behavioral therapy (CBT) Children with problematic sexual behavior CBT (PBS-CBT)	Treatment modalities that provide cognitive-behavioral, psychoeducational, and supportive services			
Not Adequately Tested				
Pharmacological treatment	There is no research validation for the use of medication targeting sexually deviant behavior in youth and only limited methodologically sound research to guide in the treatment of adults.			

Sources: Center for Sex Offender Management, 1999; National Institute of Justice, 2015; Dopp, Borduin, & Brown, 2015; Ryan, Hunter & Murrie, 2014.

#### Multisystemic Therapy for Problem Sexual Behaviors (MST-PSB)

MST-PSB is an intensive family- and community-based treatment that addresses the multiple factors of serious antisocial behavior in juvenile sexual abusers. Treatment can involve any combination of individual, family, and extra familial factors (e.g., peer, school, or neighborhood). MST-PSB promotes behavior change in the juvenile's natural environment, using the strengths of the juvenile's family, peers, school, and neighborhood to facilitate change (Center for Sex Offender Management, 1999; National Institute of Justice, n.d).

Like standard multisystemic therapy, MST-PSB specifies a model of service delivery rather than a manualized treatment with sequential session content (Dopp, Borduin, & Brown, 2015). It utilizes several standard interventions, including individual (e.g., social skills training, cognitive restructuring of thoughts about offending), family (e.g., caregiver skills training, communication skills training, martial therapy), peer (e.g., developing prosocial friendships, discouraging affiliation with delinquent and drug-using peers), and school levels (e.g., establishing improved communication between caregivers and school personnel, promoting academic achievement) (Dopp, Borduin, & Brown). The overarching goal of MST-PSB is to empower caregivers (and other important adult figures) with the skills and resources needed to address the youth's problem sexual behaviors and any other behavior problems. Services are delivered to the youth and their caregivers in home, school, and neighborhood settings at times convenient to the family (including evenings and weekends), with intensity of treatment matched to clinical need. Client contact hours are typically higher in the initial weeks of treatment (three to four times per week if indicated) and taper off during a relatively brief course of treatment (five to seven months on

average). Treatment fidelity in MST-PSB is maintained by weekly group supervision meetings involving three to four therapists and a clinical supervisor and is monitored by an MST-PSB expert using a rigorous quality assurance system (Dopp, Borduin, & Brown).

MST-PSB has been evaluated in four studies treating juveniles with illegal sexual behaviors and has been shown to be beneficial for the treatment of these youth (Dopp et al., 2016). In one significant clinical study, the results demonstrated that MST-PSB was more effective than treatment as usual (cognitive-behavioral group therapy provided by a juvenile probation department) in decreasing youth's deviant sexual interest/risk behaviors, delinquency, substance use, externalizing symptoms, and costly out-of-home placements at a 12-month post-recruitment follow-up (Dopp, Borduin, & Brown, 2015). A separate clinical study noted that MST-PSB was more effective than usual community services in improving individual symptomatology, family relations, peer relations, and academic performance (Borduin et al., as cited by Dopp, Bourduin, & Brown). Moreover, at follow-up, youth who had received MST-PSB had 83 percent fewer convictions for sexual crimes than youth receiving usual community services. MST-PSB participants also had lower recidivism rates for nonsexual crimes and spent 80 percent fewer days incarcerated than their counterparts (Borduin et al., as cited by Dopp, Bourduin, & Brown).

#### Cognitive Behavioral Therapy (CBT)

CBT is the most common modality employed by community and residential treatment programs for juvenile sexual offenders (Dopp, Borduin, & Brown, 2015). One form of CBT that has positive results is Children with Problematic Sexual Behavior—Cognitive Behavioral Therapy (PSB-CBT). The primary goal of PSB-CBT is to reduce and eliminate sexual behavior problems among school-age children. The program provides cognitive-behavioral, psychoeducational, and supportive services to children referred to the program for sexual behavior problems and their families. Intermediate goals are to increase awareness of sexual behavior rules and expectations, strengthen parent-management skills, improve parent-child communications and interactions, improve children's self-management skills related to coping and self-control, improve children's social skills, and decrease children's internalizing and externalizing behaviors (National Institute of Justice, 2015). Interventions are offered in community-based and/or residential settings and are primarily delivered in individual and/or group therapy sessions, although family sessions are frequently incorporated as well.

#### Pharmacological Interventions

The information in the following paragraph is from Ryan, Hunter, and Murrie (2014). Pharmacologic interventions may be helpful in the treatment of juvenile sexual offenders, but they should be carefully considered and utilized with caution. It is important to recognize that youth who sexually offend may also have co-occurring psychiatric disorders such as mood disorders, ADHD, thought disorders, and anxiety disorders. These disorders should be addressed with the appropriate evidence-based treatment. Treatment with pharmacologic agents that target sexually deviant behavior should always be provided on a voluntary basis, and patients and guardians should be educated about the lack of FDA approval for the use of these medications as well as the limited research regarding effectiveness. There is no research validation for the use of medication targeting sexually deviant behavior in youth and only limited methodologically sound research to guide in the treatment of adults.

In treating sexual offenders, selective serotonin reuptake inhibitors (SSRIs) have been shown to have an impact on sexual preoccupations, sexual drive, and arousal (Shaw, 1999). Further information about SSRIs is provided in the "Antidepressants and the Risk of Suicidal Behavior" section of the *Collection*.

Treating sexual offenders through the use of antiandrogen drugs should be reserved for the most severe sexual abusers and is discouraged for use in juvenile sexual offenders under age 17 (Shaw, 1999). These drugs should never be used as an exclusive treatment (AACAP).

#### Other Treatment Considerations

The following paragraphs discuss additional information of interest.

#### **Community-based Programming**

Recent research suggests that community-based programming can offer certain advantages, including shortening residential lengths of stay, reducing the number of juvenile sexual offenders placed in residential care settings, and improving the post-residential transitioning of youth back into community settings (Hunter et al., 2004). Key concepts guiding community-based programming are recognition of the heterogeneity of the population, establishment of a seamless continuum of care, emphasis on the myriad of problems this population manifests, and integration of legal and clinical management (Hunter et al.). Risk assessments guide critical decisions involving treatment intensity, supervision requirements, confinement to secure facilities, and whether a youth should be confined to a secure facility. Other guidelines to be considered when making determinations about level of care include equal emphasis on the need to:

- Maintain public safety;
- Hold offenders accountable; and
- Present offending youth with the opportunity to receive specialized treatment designed to reduce their risk of reoffending (Waite, as cited by Ryan, Hunter & Murrie, 2014).

When these elements are considered, community-based programming can be an effective element to the treatment continuum for juvenile sexual offenders. Critical to the success of community treatment is the careful integration of clinical and legal supervisory services.

#### Residential Sexual Offender Treatment

Juveniles who have significant offending histories and/or are deemed to be at a high risk to sexually re-offend are appropriate for residential sexual offender treatment. This would include those juveniles who have had multiple victims and/or have engaged in more invasive sexual offending behavior (Ryan, Hunter, & Murrie, 2014). Many of these youth have histories of substance abuse and/or treatment failure.

Residential treatment ensures public and community safety and simultaneously provides juveniles with intensive treatment that can address both sexual and non-sexual behaviors. Residential programs provide intensive treatment delivered by trained staff in a highly structured treatment setting. The key to a successful residential programming is individualizing the

treatment, which allows each juvenile to address the unique and specific issues that are relevant, so they can gain control over their sexual and non-sexual behaviors. As a result, the length of time a juvenile remains in the program will vary, depending on the severity of the juvenile's problematic behaviors and motivation in treatment.

In a study of 668 juveniles in residential sexual offender programs within Virginia's juvenile correctional centers, the recidivism rate based on re-arrests for sexual offenses was four percent (with an average time post-release of 4½ years) (Wieckowskiet et al., 2005). The projected recidivism rate for sexual offenses was 7.7 percent when based on all juveniles reaching the 10-year post-release mark (Waite et al., 2005). Successful reentry from residential program to the community was based on receiving ongoing community-based services. Juveniles who successfully complete residential programs responded best when they were provided a gradual reduction in supervision and treatment services based on their compliance with parole rules and application of material they learned in treatment.

The following information is taken from Ryan, Hunter, & Murrie (2014). It is critical that clinicians and juvenile justice professionals tasked with making disposition recommendations comprehend the implications of either under or overprescribing interventions for juvenile sexual offenders. Placement of high-risk youth in community-based programs with few external controls obviously raises the risk of the youth perpetrating new sexual and/or nonsexual offenses. These offenses not only bring harm to their victims but also lead to new, and perhaps more serious, legal and social consequences. Conversely, placing low-risk juveniles in a correctional or residential setting with juveniles who are more antisocial or sexually deviant can result in unintended and even detrimental treatment effects (Poulin, Dishion, & Burraston, as cited by Ryan, Hunter, & Murrie). For these reasons, thorough assessment is critical.

#### <u>Incorporating Trauma-Informed Care</u>

Clinicians should consider incorporating principles of trauma-informed care into evidence-based sex offender treatment models. Early adverse experiences are prevalent in sex offender populations. Early trauma paves the way for maladaptive coping and interpersonal deficits, which can lead to abusive behavior. Content-oriented sex offender treatment models should integrate process-oriented components that address the ways in which early trauma shapes cognitions and behaviors. Relational approaches to therapy can enhance the youth's interpersonal skills while improving their general well-being. This may mitigate future offending as the youth adopts and successfully practices healthier, non-destructive strategies for meeting emotional needs (Levenson, 2014).

#### **Virginia's Sexual Offender Treatment Program**

Currently, the Virginia Department of Juvenile Justice (VDJJ) provides cognitive-behavioral sexual offender evaluation and treatment services. These are provided in specialized treatment units and in the general population (VDJJ, 2016).

Inpatient and moderate treatment is delivered in a group format in self-contained units for highrisk juveniles, with inpatient treatment more intensive than moderate treatment. Prescriptive treatment is delivered individually as needed. Juveniles in sex offender treatment units receive intensive treatment by a multidisciplinary treatment team that includes a community coordinator, counselor, and specially trained therapists. Specialized sex offender treatment units offer an array of services, including individual, group, and family therapy. Each juvenile receives an individualized treatment plan that addresses programmatic goals, competencies, and core treatment activities. Successful completion of sex offender treatment may require six to 36 months depending on treatment needs, behavioral stability, and motivation of the juvenile. The median treatment time is approximately 18 months (VDJJ, 2016).

VDJJ has previously collected data on the effectiveness of this program. This data indicated that sexual recidivism rates for juvenile sexual offenders was lower than that for adult offenders and that youth participating in a self-contained sexual offender treatment program were less likely to participate in criminal activity after release. This is particularly true for the non-sexual assault offenders. The data offered two important findings:

- 1. Rates of recidivism, based on rearrests, for sexual offenses among juvenile sexual offenders are low and are not based on the type of treatment during incarceration; and
- 2. High impulsive/antisocial behaviors significantly increase the probability of recidivism, regardless of type of treatment during incarceration (Wieckowski et al., 2005).

In fiscal year 2016, over 11 percent of direct care admissions had a sex offender treatment need. Recidivism rates for juveniles assigned sex offender treatment needs were lower than rates for juveniles assigned aggression management or substance abuse treatment needs. The 12-month recidivism rates for juveniles receiving direct care sex offender treatment was 27 percent for fiscal year 2014. Conversely, the 12-month recidivism rates for juveniles receiving substance abuse treatment and aggression management was about 43 percent and 41 percent.

#### **Qualifications of Sex Offender Treatment Providers**

Due to the potential risk to the community from ineffective treatment for sexual offenders, the Virginia General Assembly passed legislation in 1997 (Chapter 556) to create a certification process for clinicians who provide service to sexual offenders. While licensed practitioners are required to practice only within the scope of their expertise (i.e., one could not provide sex offender treatment unless qualified to do so), a certification as a sexual offender treatment provider (CSOTP) offers additional evidence of a specific expertise in this area. When seeking professional services for sexual offenders, it is prudent to ensure that the qualifications of the service provider indicate expertise in the treatment of sexual offenders. One way to ensure such expertise is to select a professional with this certification (CSOTP). Qualifications include a minimum of a master's or doctoral degree in a selected field or a Doctor of Medicine (M.D.) or Doctor of Osteopathic Medicine (D.O.) degree from an institution that is approved by an accrediting agency recognized by the Virginia Board of Medicine. Qualifications also include 50 hours of sex offender treatment-specific training; 2,000 hours of post-degree clinical experience, 200 of which must be face-to-face treatment/assessment of sexual offenders; and 100 hours of face-to-face supervision within the 2,000 hours experience with a minimum of six hours per month. A minimum of 50 hours shall be in individual, face-to-face supervision. Face-to-face supervision obtained in a group setting shall include no more than six trainees in a group (Virginia Board of Psychology, Regulations Governing the Certification of Sex Offender Treatment Providers, 18 VAC 125-30 et seg.).

#### Recidivism: Research and Current Trends

Studies on sexual offending among youth suggest that, although the majority of adolescents who commit sexual offenses do not continue offending into their twenties, somewhere between 9 percent and 15 percent do (Nisbet, Wilson, & Smallbone, as cited by Chu & Thomas, 2010). Researchers are beginning to illuminate various risk factors associated with juvenile sexual reoffending in order to further propel the establishment of effective means of assessment and treatment within this population. Empirically-supported risk factors include deviant sexual interest (e.g., sexual interest in children and/or sexual violence), prior criminal sanctions for sexual offending, sexual offending against more than one victim, sexual offending with a victim not known to the offender, social isolation, and uncompleted offense-specific treatment (Worling & Langstrom, as cited by Rich, 2014). Moreover, specialized sex offender treatment may not reduce the risk of subsequent nonsexual delinquency by juvenile sexual offenders. Between one fourth and one half of sexually abusive youth engage in nonsexual delinquency following treatment (Ryan, Hunter, & Murrie, 2014). Therefore, presently available data support the belief that sexual behavior problems in youth are often present with broader psychopathology and system dysfunction. Accordingly, treatments must extend beyond the sexual behavior problem to be effective in helping these youth learn to lead productive lives.

#### **Controversial Areas of Practice**

Some areas of practice are considered ethically and legally controversial and may create special problems for juvenile sexual offending service providers (Center for Sex Offender Management, 1999; National Center on the Sexual Behavior of Youth, 2012). These include pre-adjudication evaluations, sexual offense risk assessments, polygraphs, and phallometric assessments (e.g., a type of assessment to determine sexual attraction). The issues surrounding these areas of practice relate both to their lack of overall effectiveness and lack of validity within a juvenile population.

#### Conclusion

While there appears to be a scarcity of literature regarding evidence-based treatment programs for juvenile sexual offenders, some assessment methodologies and treatments appear promising. It is expected that future research will offer a clearer understanding of juvenile sexual offenders, further refine essential and supplemental components of effective interventions, and comprehensively assess and identify youth who are at high risk of re-offending sexually. Until then, research showing that current treatment practices can be effective overall with this population is promising and offers hope for reduced rates of recidivism.

#### **Resources and Organizations**

#### American Academy of Child & Adolescent Psychiatry (AACAP)

https://www.aacap.org/

#### **Association for the Treatment of Sexual Abusers**

http://www.atsa.com/

#### **Center for Sex Offender Management (CSOM)**

http://www.csom.org/

#### **Child Welfare Information Gateway**

Juvenile Sex Offenders

https://www.childwelfare.gov/topics/can/perpetrators/perp-sexabuse/juvenile/

#### **Juvenile Forensic Evaluation Resource Center**

Sex Offender Forensic Programs

http://www.ilppp.virginia.edu/OREM/SexOffenderPrograms

#### **National Center on Sexual Behavior of Youth**

http://www.ncsby.org/

#### **National Council of Juvenile and Family Court Judges**

Juvenile Sex Offenders

https://www.ncjfcj.org/our-work/juvenile-sex-offenders

#### Office of Juvenile Justice and Delinquency Prevention (OJJDP)

Juvenile Sex Offender Research Bibliography

https://www.ojjdp.gov/juvsexoff/sexbibtopic.html

### Office of Sex Offender Sentencing, Monitoring, Apprehending, Registering, and Tracking (SMART)

https://ojp.gov/smart/

#### **Virginia Department of Juvenile Justice (VDJJ)**

http://www.djj.virginia.gov/

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# GENERAL DESCRIPTION OF PROVIDERS

#### **Psychiatrist**

A medical doctor whose education includes a medical degree and at least four additional years of study and training. Psychiatrists are licensed as physicians by their states. Psychiatrists who pass the national examination administered by the American Board of Psychiatry and Neurology become board certified in psychiatry. Psychiatrists provide medical/psychiatric evaluation and treatment for emotional and behavioral problems and psychiatric disorders. As physicians, psychiatrists can prescribe and monitor medications.

#### **Child Psychiatrist**

A licensed physician who is a fully trained psychiatrist and who has two additional years of advanced training beyond general psychiatry in work with children, adolescents and families. Child and adolescent psychiatrists who pass the national examination administered by the American Board of Psychiatry and Neurology become board certified in child and adolescent psychiatry. Child and adolescent psychiatrists provide medical/psychiatric evaluation and a full range of treatment interventions for emotional and behavioral problems and psychiatric disorders. As physicians, child and adolescent psychiatrists can prescribe and monitor medications.

#### **Psychologist**

A mental health professional with an advanced degree in psychology. Some psychologists possess a master's degree (MS) in psychology; however, most have a doctoral degree (Ph.D, Psy.D, or Ed.D) in clinical, educational, counseling, developmental, or research psychology. Psychologists are licensed in most states. Psychologists can provide psychological evaluation and treatment for emotional and behavioral problems and disorders. Psychologists can also provide psychological testing and assessments, but are unable to prescribe medications.

#### **Child Psychologist**

A licensed psychologist who specializes in providing psychological services to infants, toddlers, children, and adolescents. A child psychologist is specifically trained to diagnose and treat the psychological, cognitive, emotional, developmental, behavioral, and family problems of children.

#### **Primary Care Physician**

A physician, such as a family physician or internist, who has completed medical school, is licensed by a medical board, and is able to prescribe medications. Although a primary care physician is trained to spot mental health problems and often prescribes medications, the primary care physician does not specialize in mental health treatment.

#### **Pediatrician**

A primary care physician who focuses on the care of children from birth to 21 years of age and who specializes in preventive health maintenance for healthy children and medical care for those who are seriously or chronically ill. Pediatricians are also increasingly involved with the prevention, early detection, and management of behavioral, developmental, and functional social problems that affect children and adolescents.

#### **Psychiatric Clinical Nurse Specialist**

A registered nurse with a master's degree in psychiatric mental health nursing who is licensed by the state to provide care, counseling, and therapy to persons with psychological, emotional, and behavioral needs. An accreditation as an advanced practicing registered nurse (APRN) by an appropriate credentialing body is necessary for this provider to receive third party reimbursement.

#### **Physician Assistant**

A health care professional who is licensed to practice under the supervision of a physician and who may perform physical examinations, diagnose illnesses and, in most states, write prescriptions. The education program required for licensure is shorter in duration than medical school.

#### **Nurse Practitioner**

A nurse who has completed advanced training and who may perform physical examinations, take medical histories, counsel patients, and prescribe certain medications. Nurse practitioners hold national certification in an area of specialty (family practice, psychiatry, pediatrics, etc.), and are licensed through nursing boards. In Virginia, nurse practitioners work under the supervision of licensed physicians.

#### **Occupational Therapist**

A professional who has received training in helping people recover and gain or regain skills to promote normal growth and development.

# **Licensed Clinical Social Worker (LCSW)**

A professional who has earned a degree in social work and has been licensed to provide counseling/therapy to individuals with emotional, psychological, and/or behavioral needs. Some social workers have a bachelor's degree (BA, BSW, or BS); however most social workers have earned a master's degree (MS or MSW). In most states, social workers can take an examination to be licensed as clinical social workers. Social workers provide counseling/therapy to individuals with emotional, psychological, and/or behavioral needs.

# **Licensed Professional Counselor (LPC)**

To-Find-Help-For-Your-Child-025.aspx

A professional with a master's degree (MA or MS) or doctoral degree who has been licensed to provide counseling to individuals with psychological, emotional, and behavioral needs. LPCs must obtain supervised clinical experience and must pass a state licensing exam. LPCs are regulated by federal and state laws, as well as their own code of ethics as developed by various national organizations such as the American Counseling Association. The LPC can be found in private practice, counseling centers, group practices, family service centers, health maintenance organizations (HMOs), hospitals, and government agencies.

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# ROVIDERS LICENSED IN VIRGINIA

Mental Health professionals in Virginia are regulated by the following entities:

- Board of Counseling
- Board of Psychology
- Board of Medicine
- Board of Social Work
- Board of Nursing

# Professionals regulated by the Board of Counseling

#### Certified Substance Abuse Counselors (CSAC)

These professionals are certified to perform substance abuse treatment functions, which generally include screening, intake, orientation, assessment, recovery, relapse prevention planning, substance abuse treatment, and case management. However, CSACs must practice under the supervision of a licensed substance abuse treatment practitioner or another licensed mental health professional unless they hold another license for independent practice or are working in an exempt setting. CSACs may also supervise certified substance abuse counseling assistants.

Educational requirements: BA; additional coursework and supervised experience in substance abuse treatment

*Where found*: Inpatient substance abuse treatment centers, community services boards, private outpatient mental health, and substance abuse clinics

#### **Certified Substance Abuse Counseling Assistants**

Professionals who are certified to perform the substance abuse treatment functions of orientation, implementation of substance abuse treatment plans, case management, substance abuse or dependence crisis intervention, record keeping, and consultation with other professionals. Certified substance abuse counseling assistants may participate in recovery group discussions but cannot engage in counseling with either individuals or groups or engage in independent or autonomous practice. They act under the supervision of a certified substance abuse counselor or other licensed mental health professional.

Educational requirements: High school diploma or equivalent; 300 hours of substance abuse treatment education and experience, including 180 hours of supervised substance abuse tasks with clients

Where found: Inpatient substance abuse treatment centers, community services boards, private outpatient mental health, and substance abuse clinics.

# Licensed Professional Counselors (LPC)

LPCs are mental health professionals who are licensed to provide individual, group, family, and couples counseling. Not all counselors are LPCs.

*Educational requirements:* MA or MS; 3,400 hours of supervised residency in counseling practice, including 2000 hours of face-to-face contact with clients

Where found: Residential treatment centers, community services boards, private outpatient mental health, and substance abuse clinics

#### Licensed Substance Abuse Treatment Practitioners

These professionals are licensed to provide advanced substance abuse treatment and independent, direct, and unsupervised treatment to such individuals or groups of individuals, and to plan, evaluate, supervise, and direct substance abuse treatment provided by others.

Educational requirements: MA or MS; additional coursework and a supervised residency in substance abuse treatment

Where found: Inpatient substance abuse treatment centers, community services boards, private outpatient mental health, and substance abuse clinics

# Licensed Marriage and Family Therapists (LMFT)

LMFTs are mental health professionals licensed to provide therapy in the context of family and marital relationships. These professionals are trained in the assessment and treatment of cognitive, affective, or behavioral, mental and emotional disorders within the context of marriage and family systems through the application of therapeutic and family systems theories and techniques.

Educational requirements: MA or MS; 3,400 hours of supervised residency in marriage and family therapy practice, including 2000 hours of face-to-face contact with clients

Where found: Community services boards, private outpatient mental health and substance abuse clinics, and private practices

# Professionals regulated by the Board of Psychology

#### Certified Sex Offender Treatment Providers (CSOTP)

CSOTPs are mental health professionals from the disciplines of counseling, social work, psychology, nursing, or medicine who have received specialized training in sex offender evaluation and treatment.

Educational requirements: MA, Ph.D, Psy.D, or MD; 50 hours of training in sex offender treatment; 2000 hours of post-degree clinical experience in assessment/treatment, with at least 200 hours with sex offender clients

Where found: Residential treatment centers, therapeutic group homes, community services boards, and private outpatient mental health clinics

# Clinical Psychologists

These psychologists specialize in the practice of psychotherapy in individual, family, marital, and group settings.

Educational requirements: Ph.D or Psy.D

*Where found:* Psychiatric hospitals, residential treatment centers, community services boards, private outpatient mental health and substance abuse clinics, and private practice

# School Psychologists

These psychologists are specifically licensed to practice in a school setting.

Educational requirements: MA with an endorsement in psychology

Where found: Public and private schools, special education residential schools, special education day schools, and therapeutic day treatment centers

#### Professionals regulated by the Board of Medicine

#### **Psychiatrists**

Psychiatrists are medical doctors or physicians who are experts in the diagnosis and treatment of mental health disorders and in the use of psychotropic medication.

Educational requirements: MD, as well as completion of a multi-year residency in psychiatry, usually in a hospital setting and under supervision of senior psychiatrists

Where found: Hospitals (regular and psychiatric), community services boards, private outpatient mental health clinics, and private practice

#### Professionals regulated by the Board of Social Work

#### Licensed Clinical Social Worker (LCSW)

These social workers are professionally qualified at the autonomous practice level to provide direct diagnostic, preventive, and treatment services that may include psychotherapy and counseling for mental disorders, substance abuse, marriage and family dysfunction, and problems caused by social and psychological stress or health impairment.

Educational requirements: MSW or DSW; supervised experience in a treatment setting

Where found: Local social service agencies, hospitals (both regular and psychiatric), residential treatment centers, group homes, community services boards, and private outpatient mental health and substance abuse clinics

#### Licensed Social Workers

These professionals are trained to provide diagnostic, preventive, and treatment services, but on a supervised rather than independent basis.

Educational requirements: BA or MSW; supervised experience in a treatment setting

Where found: Local social service agencies, hospitals (both regular and psychiatric), residential treatment centers, group homes, community services boards, private outpatient mental health, and substance abuse clinics

#### **Professionals Regulated by the Board of Nursing**

#### Psychiatric Clinical Nurse Specialist

These professionals are registered nurses who have a master's degree in psychiatric mental health nursing and are licensed by the state to provide care, counseling, and therapy to persons with psychological, emotional and behavioral needs. An accreditation as an Advanced Practicing Registered Nurse (APRN) by an appropriate credentialing body is necessary for this provider to receive third party reimbursement.

Educational requirements: RN; MA in psychiatric/mental health nursing

Where found: Psychiatric hospitals, community services boards, private outpatient mental health clinics, and private practice

#### Professionals Regulated by the Board of Nursing and the Board of Medicine

#### *Nurse Practitioner (NP)*

Nurse practitioners engage in the practice of medicine in collaboration and under the medical direction and supervision of a licensed physician. "Medical direction" means the collaborative development of a written protocol between the nurse practitioners and the physician. Nurse practitioners with prescriptive authority may prescribe medication within

the scope of a written practice agreement in Virginia is regulated by the Board of Nursing and the Board of Medicine under a Committee of the Joint Boards. Nurse practitioners hold national certification in an area of specialty (family practice, psychiatry, pediatrics, etc.).

Educational requirements: RN; MA in nursing with nurse practitioner concentration; certification from a national board

Where found: Psychiatric hospitals, community services boards, private outpatient mental health clinics, and private practice

# ERMS USED IN VIRGINIA'S MENTAL HEALTH DELIVERY SYSTEM

**504 Plan** – An individualized plan developed for a student with a disability that specifies what accommodations and/or services they will get in school to "level the playing field" so that they may derive as much benefit from their public educational program as their nondisabled peers. The plan follows from the requirements of Section 504 of the Rehabilitation Act of 1973. The Act also applies to extracurricular activities and non-student situations such as employment. Section 504 applies to all public entities receiving federal monies or federal financial assistance.

**acetylcholine** – Often abbreviated *Ach*, this chemical compound is one of many neurotransmitters.

acute – Refers to an intense illness or affliction of abrupt onset.

**adaptive** – An individual's effectiveness in functioning at an age-appropriate level.

**adjustment disorder** – A disorder that occurs when a child experiences emotional and behavioral symptoms of depression and/or anxiety that is clearly in response to an identifiable stressor or stressors. The diagnosis of adjustment disorder is most appropriate when the child is experiencing distress above what might be expected in response to a stressor and/or when the stressor causes school grades to drop or impedes daily activities. *See "Adjustment Disorders" section.* 

**affective disorder** – A type of mental disorder that is not caused by detectable organic abnormalities of the brain; that is characterized by a consistent, pervasive alteration in mood; and that affects thoughts, emotions, and behaviors.

**age appropriate** – At the right level for the chronological (actual) age of the child.

**anecdotal evidence** – An informal account of evidence, often in the form of hearsay. For instance, when a patient reports he or she feels better after taking a drug, this is anecdotal evidence that the drug is effective. Anecdotal evidence has less authority than scientific evidence and is not used to support evidence-based medicine.

anhedonia – Inability to experience pleasure from activities and play.

**anticonvulsant** – A drug designed to prevent the seizures or convulsions typical of epilepsy or other convulsant disorders. Anticonvulsant medicines are also used to treat bipolar disorder and other disorders.

**anxiolytic** – Any drug used in the treatment of anxiety.

**anxiety disorders** – Disorders characterized by worries or fears that cause significant impairment in the child's functioning. When fears do not fade and begin to interfere with daily life and activities, an anxiety disorder may be present. A child with symptoms of an anxiety disorder should be promptly evaluated by a mental health professional. *See "Anxiety Disorders" section.* 

**anorexia nervosa** – An eating disorder characterized by low body weight (less than 85% of normal weight for height and age), a distorted body image, and an intense fear of gaining weight. *See "Feeding and Eating Disorders" section.* 

**antidepressants** – Medications used in the treatment of depression, as well as other psychiatric disorders.

**antipsychotics** – Medications used to treat psychotic symptoms such as hallucinations, bizarre behavior, and delusions. There are two classes of antipsychotics: neuroleptics (also known as typical antipsychotics) and atypical antipsychotics (e.g., risperidone). Atypical antipsychotics usually have fewer side effects and are sometimes used in an off-label capacity to treat nonpsychotic symptoms such as aggression.

Asperger's syndrome – A type of pervasive developmental disorder (PDD) characterized by problems in development of social skills and behavior. The *DSM-IV* classification defines Asperger's syndrome on the basis of the presence of impairments in social interaction like those observed in autism, but without the significant delay in language or cognitive behavior. In May 2013, the American Psychiatric Association released the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, which acknowledges that all categories of autism are on a spectrum, thus eliminating the diagnosis Asperger's syndrome and replacing it with autism spectrum disorder. Research studies and clinicians may still use the term Asperger's syndrome. *See "Autism Spectrum Disorder" section.* 

**assessment** – A professional review of a child's and family's needs conducted when they first seek services from a health care professional. It typically includes a review of physical and mental health, intelligence, school performance, family situation, and behavior in the community. The assessment identifies the strengths of the child and family. Together, the caregiver and family decide what kind of treatment and supports, if any, are needed.

**assistive technology** – Any item, piece of equipment, or product system that is used to increase, maintain, or improve the functional capabilities of persons with disabilities. Wheelchairs, hearing aids, and computer screen readers are all examples of assistive technologies.

**attention-deficit/hyperactivity disorder (ADHD)** – A neurodevelopmental disorder, usually first diagnosed in childhood, that is characterized by inattention, impulsivity and, in some cases, hyperactivity. *See "Attention-Deficit/Hyperactivity Disorder" section.* 

**autism spectrum disorder** (**ASD**) – A lifelong developmental disability that typically appears during the first three years of life. A child with ASD appears to live in his/her own world, showing little interest in others, and has a lack of social awareness. Children with ASD often have problems in communication, avoid eye contact, and show limited attachment to others. No

known factors in the psychological environment of a child have been shown to cause ASD. See "Autism Spectrum Disorder" section.

**autonomic nervous system** – The autonomic nervous system controls involuntary actions, such as heartbeat and the widening or narrowing of blood vessels.

**autosomal dominant disorder** – A disorder caused by a dominant mutant gene on an autosome, i.e., genetic defect. *See "Motor Disorders" section*.

**behavior therapy** – A form of psychotherapy in which a therapist analyzes a person's problematic behavior in terms of what reinforces or punishes that behavior. The behavioral therapist will systematically alter the reinforcers or punishers to help the person to change his or her behaviors. Behavior therapy has been adapted over the years into a type of therapy called cognitive behavioral therapy (CBT), which looks at the role of both thinking (cognition) and behavior in the context of human problems.

**behavioral classroom management (BCM)** – Teacher-implemented behavior modification strategies, including reward programs, point systems, and time-outs.

behavior intervention plan (BIP) – A formalized plan that targets specific behaviors for alteration and that follows a functional behavioral assessment. BIPs are usually appended to a student's individualized educational plan. A public school must attempt such a plan before changing a student's placement to a more restrictive environment (unless there is an emergency situation). The plan is supposed to be based on positive inducements, if possible. A behavior intervention plan should also detail the environmental or proactive changes the staff will make to decrease the likelihood of the undesirable behavior or symptom.

**behavioral health authorities (BHAs)** – Agencies functioning in the same capacity and operating under the same requirements as community services boards.

**behavioral parent training (BPT)** – A technique for teaching management and discipline skills to parents so that treatment can continue in the home.

**beta-blocker** – a type of medication that inhibits the action of beta-adrenergic receptors, slowing cardiac and respiratory functions and constricting blood vessels. Beta-blockers are of value in the treatment of hypertension, cardiac arrhythmias, and migraine. In psychiatry, they are used in the treatment of aggression and violence, anxiety-related tremors, lithium-induced tremors, social phobias, panic states, and alcohol withdrawal.

**binge eating disorder (BED)** – A disorder resembling bulimia nervosa that is characterized by episodes of uncontrolled eating (or bingeing). It differs from bulimia, however, in that its sufferers do not purge their bodies of the excess food. *See "Feeding and Eating Disorders" section.* 

**biofeedback** – A technique for learning to consciously control bodily functions that are usually thought to be involuntary. The procedure uses electronic equipment to monitor some feature of physiological response (e.g., heart rate, breathing, or muscle tension) and convert the

measurement into a signal that a person can easily perceive, usually via a computer monitor. The person can then attempt to use conscious control to alter the signal.

**biological factors** – In the context of mental health disorders, biological factors include factors such as genetics or the physical functioning of the brain.

**bipolar disorder** – A mood disorder causing a child's moods to swing between states of depression (low mood and energy) and mania (heightened elevated, ecstatic mood and energy). *See "Bipolar and Related Disorders" section.* 

**body-focused repetitive behavior** – Recurrent actions that cause physical damage to oneself, or unintentional and compulsive actions that serve to relieve anxiety. Includes excoriation and trichotillomania. *See "Obsessive-Compulsive and Related Disorders" section.* 

**body image** – One's sense of one's own body, which can be linked to one's sense of self-worth.

**borderline personality disorder (BPD)** – A pattern of behavior characterized by impulsive acts, intense but chaotic relationships with others, identity problems, and emotional instability.

**broadband tool** – A general screening tool that can detect a large number of disorders.

**bulimia nervosa** – A pattern of behavior in which the individual eats excessive quantities of food and then purges the body by using laxatives, enemas, diuretics, vomiting, and/or exercising. *See "Feeding and Eating Disorders" section*.

**case management** – A service that assists children and their families in identifying and accessing services that meet their individual needs. The primary purpose of case management is to ensure that the needed services are delivered in an effective and efficient manner. The activities of a case manager may include identifying and reaching out to individuals in need of assistance, assessing needs and planning services, linking the individual to supports and services, coordinating services with other providers, monitoring service delivery, and advocating for these children in response to their changing needs. Case management services are typically provided by community services boards, private clinics, and social services agencies.

**case manager** – A health care professional who works directly with clients, coordinates various activities, and acts as the clients' primary contact with other members of the treatment team. Case managers are often social workers.

**catatonia** – A cluster of motor features that includes rigid posture, fixed staring, and stupor. Catatonia manifests in a variety of mental health disorders.

**catatonic** – A person who has features of catatonia.

**causal relationship** – When scientific research has determined that one variable truly causes change(s) in another variable. Different from correlation, which means that two variables occur together a statistically significant amount of the time but that one does not necessarily cause the other to occur.

**cerebral cortex** – The outer layer of the brain, which controls voluntary motor and visual functions. The cerebral cortex plays a key role in memory, attention, perceptual awareness, thought, language and consciousness. Also referred to as the cortex.

**children's advocacy center** – A facility used for investigation, treatment, and prevention of child abuse cases that is child-friendly, safe, and supportive.

Children's Services Act (CSA) – A Virginia law that created a collaborative system in which state and local agencies work together and draw on the same pool of funds to plan and provide services for at-risk youth. The purpose of the Act is to provide high quality, child-centered, family-focused, cost effective, community-based services to high-risk youth and their families. The two primary teams that operate under the CSA are Family Assessment and Planning Teams (FAPTs) and Community Policy and Management Teams (CPMTs).

**chronic** – A term used to describe long-term persistence. In some mental health disorders, *chronic* is specified as persisting for six months or longer.

clinical trials or studies – Research studies designed to test how well new medical approaches work and to answer scientific questions about better ways to prevent, screen for, diagnose or treat a disease. They may also compare a new treatment to a treatment that is already available. Every clinical trial has a protocol, or action plan; the plan describes the trial's goal and how it will be conducted. An independent committee of physicians, statisticians and members of the community must approve and monitor the protocol and ensure that risks are worth the potential benefits.

**cognitive behavioral therapy (CBT)** – A form of psychotherapy that helps people learn to change inappropriate or negative thought patterns and behaviors associated with their illness. The goal is to recognize negative thoughts or mind-sets (mental processes such as perceiving, remembering, reasoning, decision making, and problem solving) and replace them with positive thoughts or thoughts that better reflect reality, which can lead to more appropriate and beneficial behavior. For instance, cognitive behavioral therapy tries to replace thoughts that lead to low self-esteem ("I can't do anything right") with reality-based positive expectations ("I do many things right and can do this right, too").

**cognitive impairment** – A term that describes poor mental function that affects the ability to think, concentrate, formulate ideas, reason, and remember. It is distinct from a learning disability insofar as cognitive impairment may have been acquired as a result of an accident or illness.

**community-based care** – Care and supports rendered outside the institutional setting. Treatment is provided where the child lives, goes to school, and plays.

community policy and management teams (CPMTs) – These are teams that operate under the Comprehensive Services Act to coordinate agency efforts, manage available funds, and see that eligible youths and their families get the assistance they need. CPMTs coordinate long-range, community wide planning that ensures that resources and services needed by children and families are developed and maintained in communities. CPMTs establish policies governing referrals and reviews of children and families to the Family Assessment and Planning Teams (FAPTs). Each CPMT establishes and appoints one or more FAPT based on the needs of the

community. CPMTs also authorize and monitor the use of funds by each FAPT. The CPMT includes a representative from the following community agencies: Community Services Board, Juvenile Court Services Unit, Department of Health, Department of Social Services, and the local school division. The team also includes a parent representative and a private provider organization representative for children or family services, if such organizations are located within the locality.

**community services boards** (**CSBs**) – These agencies serve as the single point of entry into the publicly-funded mental health system. They provide comprehensive mental health, intellectual disability, and substance abuse services. There are 39 CSBs throughout the Commonwealth. Because these agencies are affiliated with local governments, there is tremendous variation in the number and types of services offered by each. However, CSBs usually provide certain core services: crisis intervention services, local inpatient services, outpatient services, case management, day support, residential services, and early intervention services.

**comorbidity** – A condition in which an individual is diagnosed with more than one disorder at the same time. When those disorders are related to mental health and substance use, the term cooccurring disorder or dual diagnosis is sometimes used.

**complex trauma** – Multiple traumatic events experienced by a child that occur within the caregiving system, where safety and stability would be expected. *See "Trauma- and Stressor-Related Disorders" section.* 

**compulsion** – In terms of children's mental health, a compulsion is a repetitive behavior (such as hand washing) or mental act (such as praying or counting) that a child is driven to complete. Compulsive acts are often used to reduce anxiety or distress, though there is no connection between the act and the distress.

**conduct disorder (CD)** – Children with CD exhibit persistent and critical patterns of misbehavior. These children may indulge in frequent temper-tantrums like children with oppositional defiant disorder (ODD); however, they also violate the rights of others. *See "Disruptive, Impulse Control & Conduct Disorders" section.* 

**contamination obsessions** – Obsessions characterized by intrusive thoughts about catching a disease from touching a surface, which leads to compulsive grooming or hand-washing.

**contingency management strategies** – Strategies that use reward systems designed to provide reinforcements to increase desired behaviors, such as following directions or taking turns.

**continuum of care** – The delivery of healthcare provided over a period of time. Continuum of care typically describes the process of guiding the patient through various stages of care and tracking and managing needs and progress.

**contraindicated** – To indicate the inadvisability of a medical treatment.

**co-occurring disorder** – In the field of mental health, this term typically refers to patients who have substance-related and mental health disorders (e.g., opioid use disorder and depression) or

neurodevelopmental disorders and mental health disorders (e.g., ADHD and bipolar disorder). Also known as dual diagnosis.

**coprolalia** – Vocal tic activity that usually involves loud grunting, but may also include word shouting, with the words sometimes being obscenities. *See "Motor Disorders" section*.

**cortex** – The outer layer of the brain, which controls voluntary motor and visual functions. The cortex plays a key role in memory, attention, perceptual awareness, thought, language and consciousness. Also referred to as the cerebral cortex.

**correlation** – When scientific research has determined that two variables occur together a statistically significant amount of the time. A correlation does not prove a causal relationship (or that one of the variables caused the other variable to occur).

**cortisol** – A hormone produced in the presence of stress.

**counseling** – A service that incorporates care consultation, evaluation, and outpatient treatment to those experiencing concerns about their mental health.

**court service units** (**CSU**) – Local agencies operated by the Department of Juvenile Justice that serve as gatekeepers for children and families served by the local Juvenile and Domestic Relations Court. These units are responsible for handling petitions, intakes, investigations and reports, custody investigations, and probation supervision.

**CREB** – A gene linked to alcohol addiction, as well as anxiety-like behaviors.

**criteria** – A specifier or criteria is a specific symptom or characteristic used to diagnose a mental health disorder.

**crisis intervention (emergency) services** – 24-hour services that may be provided in either residential or nonresidential settings. These are short term interventions designed for children and adolescents who experience periodic crisis or acute episodes that require special services. The underlying goal of these services is to assist the child and family in resolving the situation so that inpatient hospitalization is unnecessary. Nonresidential crisis services include telephone hotlines, walk-in crisis intervention services, mobile crisis outreach services, and intensive home-based interventions. Residential services include runaway shelters, crisis stabilization units, and temporary placements in programs such as therapeutic foster care and crisis group homes.

**cultural competence** – A term that refers to improving the effectiveness of services through being sensitive and responsive to the cultural norms of the client. Culturally competent service providers are aware of the impact of their own culture and possess skills that help them to provide services that are culturally appropriate in terms of the values, customs, and beliefs of their client's culture. (A person can identify with a culture based on race, ethnicity, nationality, religion, sexual orientation, class, and so forth.)

**cycling** – A repeated, sequential event that can increase or subside. This term is often used in reference to mood swings.

**cyclothymic disorder** – A mild form of bipolar disorder that causes emotional ups and downs.

**daily report card** – One strategy of behavioral classroom management that provides feedback to parents and/or the therapist about a child's progress in achieving target behaviors.

**day treatment services** – See therapeutic day treatment.

day support waiver – See Medicaid Waiver Program.

**delusion** – A fixed false belief that is resistant to reason or confrontation with actual fact.

**Department of Behavioral Health and Development Services (DBHDS)** – Formerly the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS), the Department's name was changed by the 2008 Virginia General Assembly.

**depression** – A depressive disorder characterized by extreme feelings of sadness, lack of selfworth, and dejection. *See "Depressive Disorders" section.* 

**developmental disabilities** – A group of conditions caused by an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime.

*Diagnostic and Statistical Manual of Mental Disorders* – Official manual listing psychiatric and psychological disorders, published by the American Psychiatric Association and recognized by both mental health professionals and the insurance industry as the primary authority for the diagnosis of mental disorders. The latest revision was the *DSM Fifth Edition (DSM-5) (2013)*, which replaced the *DSM Fourth Edition, Text Revision (DSM-IV-TR) (2000)*.

**diagnostic assessment** – A formal process by which a health problem or problems are identified and/or measured.

dialectical behavioral therapy (DBT) – A cognitive-behavioral treatment approach with two key characteristics: a behavioral, problem-solving focus blended with acceptance-based strategies, and an emphasis on dialectical processes. "Dialectical" refers to the issues involved in treating patients with multiple disorders and to the type of thought processes and behavioral styles used in the treatment strategies. DBT emphasizes balancing behavioral change, problem-solving, and emotional regulation with validation, mindfulness, and acceptance of patients.

**dietary supplement** – A product taken by mouth that contains an ingredient intended to supplement the diet. Ingredients may include, but are not limited to, vitamins, minerals, herbs or other botanicals, amino acids, and substances such as enzymes. Dietary supplements are placed in a special category under the general umbrella of foods and are not regulated by the Food and Drug Administration.

**disassociation** – A mental process in which a person consciously or unconsciously detaches (or disassociates) his or her thought processes about an experience from the emotions those experiences provoke. Disassociation can be an unhealthy coping strategy for dealing with traumatic experiences and/or a symptom of a mental health disorder.

**discharge plan** – A document that summarizes information pertaining to a person's stay in a health care facility and identifies what needs to occur post-discharge.

**disinhibition** – A lack of restraint with impulsivity driven by current thoughts or feelings without regard to consequences. Unconscious disinhibition can be a symptom of a mental health disorder.

**disruptive disorders** – These disorders are the most common reasons children are referred for mental health evaluations and treatment. Disruptive disorders include mental health problems with a focus on behaviors that both identify emotional problems and create interpersonal and social problems for children and adolescents in the course of their development. Conduct disorder and oppositional defiant disorder are two classes of disruptive disorders. *See* "Disruptive, Impulse Control & Conduct Disorders" section.

**disruptive mood dysregulation disorder** – A new diagnosis to the *DSM-5*, this disorder applies to children up to age 18 who exhibit persistent irritability and frequent episodes of extreme inability to control their behavior.

**dopamine** – A neurotransmitter associated with attention, learning, and pleasure.

**double-blind study** – A scientific study in which neither the researchers nor the participants know details about the treatment received, including which participants received placebos. The goal of a double-blind study is to prevent bias or other factors to affect results.

**dual diagnosis** – See co-occurring disorder.

**dysfunction** – Abnormal or impaired functioning, especially of a bodily system or social group.

**dyslexia** – A type of learning disability characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities.

**dysphoria** – Intense depressive and discontented feelings, often coupled with indifference.

**dysthymia** – See persistent depressive disorder (dysthymia).

early intervention services – Services intended to improve functioning or change behavior in children identified as experiencing problems, symptoms, or behaviors. The goal is to improve the child's behaviors in order to prevent a future need for more extensive treatment. This approach also includes infant and toddler intervention, which provides family-centered, community-based early intervention services designed to meet the developmental needs of infants and toddlers and their families to enhance the child's development and to prevent or minimize the potential for developmental delays. These types of services are most often provided by social service agencies, community services boards, pediatricians and nurses in health clinics, and schools.

Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) – Medicaid's comprehensive and preventive child health program for individuals under the age of 21. The EPSDT program covers screening and diagnostic services to determine physical or mental defects in recipients and health care, treatment, and other measures to correct or ameliorate any

defects and chronic conditions discovered. Services include health and developmental history screening, immunization, nutritional status assessment, vision and hearing testing, dental services for children three years and older, and visual treatment including eyeglasses.

eating disorders – Refers to a variety of life threatening mental health disorders characterized by abnormal eating behaviors. *See "Feeding and Eating Disorders" section*.

**echolalia** – The involuntary parrot-like repetition (echoing) of a word or phrase spoken by another person. Echolalia is a feature of disorders including schizophrenia, (especially the catatonic form) and Tourette syndrome.

**echopraxia** – The involuntary imitation of the movements of another person. Echopraxia is a feature of disorders including schizophrenia, (especially the catatonic form) and Tourette syndrome.

efficacy/efficacious – Producing, or capable of producing, a desired effect.

**electroconvulsive therapy** (**ECT**) – A treatment usually reserved for very severe or psychotic depressions or manic states that are not responsive to medication treatment. A low-voltage electric current is sent to the brain of an anesthetized patient to induce a convulsion or seizure, which has a therapeutic effect.

**emotional lability** – Emotional instability; intense and easily aroused emotions out of proportion to circumstances.

**empirical** – Capable of being verified or disproved by observation or experiment.

**enuresis** – Bed wetting.

**epigenetics** – The study of changes in organisms caused by modification of gene expression rather than alteration of the genetic code itself. Epigenetics describes how genes can be turned on or off when an organism (such as a human being) is exposed to various environmental factors.

**episodic** – Reflecting a series of episodes.

**ethnopharmacology** – Treatment that acknowledges that people may have different reactions to medications based on their racial or ethnic background. For instance, Asian and Hispanic children with schizophrenia may require lower doses of antipsychotics than Caucasians to achieve the same blood levels. Although knowledge in this area is scant, cultural patterns should be considered in prescription practices.

**etiology** – A process that describes how a problem or diagnosis developed to its current condition.

**evidence-based** – Treatments that have undergone scientific evaluation and are proven to be effective.

**excoriation** (**skin-picking**) **disorder** – A new DSM-5 disorder characterized by recurrent skin picking resulting in skin lesions. *See "Obsessive-compulsive and Related Disorders" section.* 

**executive functioning** – An umbrella term for the cognitive skills involved in mental control and self-regulation.

**exposure therapy** – A form of psychotherapy in which a patient is deliberately exposed, under controlled conditions, to the problem or event that triggers psychological problems with the aim of reducing the impact of the triggering event.

**Family Access to Medical Insurance Security (FAMIS)** – Virginia's Title XXI Plan that helps families provide health insurance to their children.

family assessment and planning teams (FAPTs) – Local teams that operate through the Comprehensive Services Act. The purpose of the team is to assess the strengths and needs of troubled youths and families who are approved for referral to the team and identify and determine the services that are necessary to meet these unique needs. They are responsible for developing an individual family services plan (IFSP) for appropriate and cost-effective services, and for monitoring the child's progress under this plan.

**family preservation services** – See home-based services.

**family support services** – Services that are designed to assist families in dealing with the pressures and demands of raising children with severe emotional disturbance. A variety of services are provided to assist families in achieving balanced lives, including respite care, family self-help, support, and advocacy groups, and assistance with financial or family survival needs (food, housing, transportation, home maintenance). Family support services may also include providing caregivers with the necessary education, information, and referrals to ensure that they are informed decision-makers. These services are typically provided by social service agencies, community services boards, and private agencies and organizations.

familial – Tending to occur in more members of a family than expected by chance alone.

**family systems therapy** – A form of psychotherapy that focuses on how a child interacts with his/her most important social environment, the family. The underlying premise of the therapy is that the child's problems are best understood by observing how they fit into the larger scheme of relationships among the members of the family group.

**fetal alcohol syndrome** – A condition affecting the children of mothers who consume large quantities of alcohol during pregnancy; it can involve cognitive delays, attention difficulties, and physical and emotional disability. Deficits range from mild to severe, including growth retardation, brain damage, intellectual disability, anomalies of the face, and heart failure.

Free Appropriate Public Education (FAPE) – A statutory requirement that children with disabilities receive a public education appropriate to their needs, at no cost to their families.

**functional family therapy** (**FFT**) – A family-based prevention and intervention program that combines and integrates established clinical therapy, empirically supported principles, and extensive clinical experience.

**generalized anxiety disorder** – A mental disorder characterized by chronic, excessive worry and fear that seems to have no real cause. Children or adolescents with generalized anxiety disorder often worry a lot about things such as future events, past behaviors, social acceptance, family matters, their personal abilities, and/or school performance. *See "Anxiety Disorders" section.* 

**group homes** – See therapeutic group homes.

**habit reversal therapy** – Includes awareness training, competing response training and social support. *See "Motor Disorders" section.* 

**halfway houses** – See therapeutic group homes.

**hallucinations** – A strong perception of an event or object when no such situation is present; may occur in any of the senses (i.e., visual, auditory, gustatory, olfactory, or tactile).

**health maintenance organization (HMO)** – A medical care organization organized to deliver and finance health care services through a network of participating providers. An HMO provides comprehensive health care services to its members for a fixed prepaid premium. A primary care physician must provide or authorize all services provided to members. Members must use innetwork physicians.

**heritability** – Measure of the degree to which the variance in the distribution of a phenotype is due to genetic causes or non-genetic factors.

**hoarding disorder** – The ongoing inability to discard or part with possessions, regardless of the value attributable by others. Hoarding may cause emotional, financial, legal, and physical harm to the affected individual as a result of the disorder. *See "Obsessive-compulsive and Related Disorders" section.* 

home-based services (family preservation services) – Services typically provided in the residence of an individual who is at risk of being moved into an out-of-home placement or who is being transitioned back into the home from an out-of-home placement. The treatments are family-focused and involve working within the home environment to preserve the family structure. The services may include crisis treatment, intensive case management, individual and family counseling, skill building (life, communication, and parenting), 24-hour emergency response, and assisting in obtaining and coordinating needed services, resources, and supports. Services vary based on the goals of the program and the needs of the family. The services tend to be of short duration (1 to 3 months) but highly intensive (5 to 20 hours per week). They are usually provided only when other interventions have proven unsuccessful. They are typically offered through child welfare agencies, community services boards, mental health centers, hospitals, juvenile justice agencies, or private providers.

**hypersexuality** – Being excessively interested or involved in sexual activity.

**hypersomnia** – Excessive sleepiness.

**hypervigilance** – Watchfulness or awareness of one's surroundings over and above what is normal.

**hypoxia** – Lack of oxygen supply.

**independent living services** – Programs specifically designed to help adolescents make the transition to living independently as adults. They provide training in daily living skills (financial, medical, housing, transportation) as well as vocational and job training. They are offered by therapeutic group homes, residential treatment centers, day treatment programs, community services boards, and private clinics.

**individualized educational program (IEP)** – A plan developed by parents, teachers, school administrators, and the student to meet the unique educational needs of a student with a disability. The plan should describe the services that are to be provided by the school system within the context of the educational program and contain specific objectives and goals.

**Individuals with Disabilities Act (IDEA)** – Federal law mandating that a free and appropriate public education be available to all school-age children with disabilities. Also known as Public Law 105-17.

**inpatient hospitalization** – Services provided on a 24-hour basis in a hospital setting. Tends to be reserved for children with difficult and ongoing problems. Inpatient hospitalization programs use a variety of interventions, including individual, group, and family therapy, medication management, and behavior modification.

**institute for mental disease (IMD)** – A residential facility with more than 16 beds that specializes in psychiatric care.

**intellectual disability** – Previously termed "mental retardation," intellectual disability is characterized both by a significantly below-average score on a test of mental ability or intelligence and by limitations in the ability to function in areas of daily life, such as communication, self-care, and getting along in social situations and school activities. *See* "*Intellectual Disability*" *section*.

**intellectual disability waiver** – See Medicaid Waver Program.

**interpersonal rejection sensitivity** – Hyper-alertness to the social reactions of others, often characterized by anxiously expecting and rapidly perceiving and overreacting to social rejection.

**intervention** – An action intended to modify a negative state with the goal of improving it. For instance, psychotherapy is one intervention for a mental health disorder such as depression.

**intensive outpatient therapy (IOP)** – A form of partial hospitalization that is more intense than regular once-per-week outpatient therapy and less intense than full inpatient hospitalization. Patients often participate in therapy several days per week for several hours at a time. This type of treatment is typically shorter in duration than full partial hospitalization programs.

**intermediate care facility** – An institution that provides health-related care and services to individuals who do not require the degree of care provided by hospitals or skilled nursing facilities as defined under Title XIX (Medicaid) of the Social Security Act.

intermediate care facilities for persons with mental retardation (ICF/MR) – Facilities providing a community-based residential setting for individuals with mental retardation who also have severe medical needs. They offer rehabilitative services designed to maximize independence and enhance the resident's quality of life. They provide residential care, skilled nursing, and specialized training, and may include training programs in language, self-care, independent living, socialization, academic skills, and motor development. While ICF/MRs most often serve adults, adolescents can sometimes be placed in these programs.

**interpersonal therapy** – A form of psychotherapy that focuses on improving interpersonal skills by exploring the relationships that the patient has with others. Patients learn to evaluate their interactions with others and to become aware of self-isolation and social difficulties.

**intrusive aversive therapy** – A formal behavior management technique designed to reduce or eliminate severely maladaptive, violent, or self-injurious behavior by using negative stimuli when problem behaviors are exhibited. It does not include verbal therapies, seclusion, physical or mechanical restraints used in conformity with the applicable human rights regulations, or psychotropic medications.

**juvenile correctional centers** (**JCCs**) – Secure residential facilities operated by the Virginia Department of Juvenile Justice. Juvenile offenders are committed to JCCs by the Juvenile and Domestic Relations District Courts and Circuit Courts for rehabilitation and confinement. These facilities provide programs to address the treatment, disciplinary, medical, and recreational needs of the juveniles.

**juvenile sex offender** – Juvenile perpetrating sex offense(s) by committing any sexual act against the victims' will, without consent, or in an aggressive, exploitive, or threatening manner. *See "Sexual Offending" section.* 

**labile moods/mood lability** – See emotional lability.

**license/licensure** – Permission granted to an individual or organization by a competent authority (such as state government) to engage lawfully in a practice, occupation, or activity. Licensure is usually granted based on examination and/or proof of education rather than on measures of performance. A license is usually permanent, but may be conditioned on annual payment of a fee, proof of continuing education, or proof of competence.

**limbic system** – A group of interconnected brain structures, common to all mammals, which support a variety of functions, including emotion, motivation, and behavior.

**lithium** – A type of mood stabilizing medication.

**major depressive disorder** – One or more major depressive episodes without a history of mania. *See "Depressive Disorders" section*.

**mandated** – In terms of children's mental health, required by law. This designation can refer to children receiving funding under the Comprehensive Services Act. State and local governments are required by law to appropriate sufficient funds for services for these youth. Children and adolescents who fall within this category are generally those who receive individualized services from the education and foster care systems.

**mania** – A distinct period of abnormally and persistently elevated, expansive, or irritable mood. *See "Bipolar and Related Disorders" section.* 

**massed negative practice** – One of the most frequently used behavioral therapy techniques in the treatment of children with tic disorder in which the individual is asked to deliberately perform the tic movement for specified periods of time interspersed with brief periods of rest.

**Medicaid** – The federal program (Title XIX of the Social Security Act) that pays for health services for certain categories of people who are poor, elderly, blind, disabled, pregnant, or caretaker relatives of children under the age of 18 and who meet financial eligibility criteria.

Medicaid Waiver Program – In Virginia, the Medicaid Waiver Program provides services to individuals with disabilities. Includes the Intellectual Disability Waiver and the Individual & Family Development Disabilities Support Waiver. Also includes the Day Waiver Program, which provides services such as day support, pre-vocational services, and supported employment for individuals on the waiting lists for the intellectual disability and developmental disability waivers.

**Medicare** – The federal health insurance program for people who are 65 or older.

mental retardation – See "intellectual disability."

mentorship services – Individuals who serve as role models and caring adult support figures outside of the immediate family, and often serve a protective role in the lives of at-risk youth. They can be citizen volunteers or paid paraprofessionals. Their primary role is to assist the youth's development of social support and social skills, competencies and confidence, and to provide school support. Some specific activities include crisis intervention and problem solving, academic assistance, vocational support and recreation, and most importantly, developing a supportive and helpful relationship with the child. This is accomplished through regularly scheduled contact, which is often daily. These types of services may be provided by community services boards, social service agencies, private clinics, and volunteer agencies.

**methadone detoxification and maintenance** – Services that combine outpatient treatment with the administering of methadone as a substitute narcotic drug, in decreasing doses, until the individual reaches a drug-free state. These treatments usually do not last longer than 180 days. They are typically provided by substance abuse treatment centers.

**modality** – A therapeutic treatment or agent.

**mood disorders** – Category of mental health problems that result in elevating or lowering an individual's mood.

**mood stabilizer** – Medication used in the treatment of bipolar disorder to suppress swings between mania and depression. Lithium is a commonly-used mood stabilizer.

**multidimensional family therapy (MDFT)** – An outpatient, family-based treatment for teenagers with serious substance abuse issues. This approach views drug use in terms of network of influences (individual, family, peer, community) and encourages treatment across settings in multiple ways. Sessions may be held in a clinic, home, court, school, or other community locations. *See "Substance Use Disorders" section*.

**multimodal** – Having or involving several types of therapies or treatment approaches.

**multisystemic therapy** (**MST**) – An integrative, family-based treatment with focus on improving psychosocial functioning for youth and families so that the need for out-of-home placements is reduced or eliminated.

**narrowband tool** – A screening tool specific to a disorder. Opposite of a broadband tool.

**neurobiology** – The branch of biology that deals with the anatomy, physiology, and pathology of the nervous system.

**neuroimaging** – Use of various techniques to either directly or indirectly image the structure or functioning of the brain.

**neuroleptic** – A term that refers to older (typical) antipsychotic medications. Neuroleptic drugs reduce confusion and agitation and psychotic symptoms such as hallucinations and delusions.

**neurological** – Pertaining to the brain and nervous system.

**neuropsychiatry** – A branch of medicine that deals with mental disorders attributed to diseases or disorders of the brain and nervous system, including neurodevelopmental disorders.

**neurotransmitters** – In the brain, these chemicals transfer messages from one nerve cell to another and affect mood.

**non-mandated** – In children's mental health services, not required by law. This designation is given to youths who are referred for services under the Children's Services Act for which the Commonwealth is not required to provide complete funding. Children and adolescents who fall into this category are generally referred for treatment by the juvenile justice or mental health systems.

**norepinephrine** – A hormone that regulates blood pressure by causing blood vessels to narrow and the heart to beat faster.

**nucleus accumbens** – The key structure of the brain responsible for reward, motivation, and addiction. Substances such as cocaine and nicotine trigger the release of dopamine in this region.

**nystagmus** – Rapid eye movement that may be used by physicians to diagnose intoxication and/or signs of substance use.

**obsession** – Unwanted ongoing urges or thoughts that cause anxiety and stress. Some individuals try to ignore or suppress obsessions by completing another thought or action.

**obsessive-compulsive disorder (OCD)** – A disorder in which a person has an unreasonable thought, fear, or worry that he/she tries to manage through a ritualized activity to reduce the anxiety. Frequently occurring disturbing thoughts or images are called obsessions, and the rituals performed to try to prevent or dispel them are called compulsions. *See "Obsessive-Compulsive and Related Disorders" section.* 

**off-label use** – The legal practice of prescribing a medication in a way that was not originally intended by the manufacturer.

Office of Juvenile Justice and Delinquency Prevention (OJJDP) – A federal agency within the U.S. Department of Justice that coordinates and provides resources to state and communities pertaining to juvenile justice system.

**operant conditioning** – A process of behavior modification in which the likelihood of a specific behavior is increased or decreased through positive or negative reinforcement, so that the subject comes to associate the pleasure or displeasure of the reinforcement with the behavior.

**oppositional defiant disorder (ODD)** – An enduring pattern of uncooperative, defiant and hostile behavior to authority figures that does not involve major antisocial violations. *See "Disruptive, Impulse-Control, and Conduct Disorders" section.* 

outpatient psychiatric services – Services provided to individuals, groups, or families on an hourly schedule. Outpatient services are the most frequently used treatment method for children, and may either be provided for a short term (6 to 12 sessions) or a longer duration (a year or longer). Services are generally provided on a weekly basis, if not more often, depending on the individual needs of the child and family. However, under managed care and most insurance plans, brief therapy is likely to be mandated. It is the least restrictive form of service for children and families, and it is provided in a number of settings, including community services boards, outpatient psychiatry departments of hospitals, and private offices. It is most often provided by psychiatrists, psychologists, social workers, and counselors. Treatment efforts may include diagnosis and evaluation, intake and screening, counseling, psychotherapy, behavior management, psychological testing and assessment, and medication management. These services are typically offered in community services boards, private clinics and offices, and outpatient psychiatry departments of hospitals.

**panic attack** – A distinct period of unexpected terror. Symptoms like shortness of breath, pounding heart, and fear of losing control may accompany the attack, which may be expected or a surprise. Panic attacks are sometimes mistaken for heart attacks or other health problems by the person experiencing the attack.

**panic disorder** – A disorder characterized by separate from agoraphobia in *DSM-5*.

**paraphilia** – A term referring to the repeated, intense sexual arousal to unconventional and socially deviant stimuli.

**parent** – A parent, a guardian, or a person acting as a parent in the absence of a parental guardian. The term "parent" also means a surrogate parent appointed pursuant to Virginia regulations.

**partial hospitalization** – A form of therapeutic day treatment that is based in a psychiatric hospital. It provides the use of a psychiatric hospital setting during the day, with children returning to their home each night. It is frequently used for those children who are being released from a psychiatric hospital and must transition back into the community and the school system. It is also used to assist youths at risk of inpatient hospitalization. See therapeutic day treatment.

**pathological** – Related to or caused by a mental health disorder or disease.

**persistent depressive disorder (dysthymia)** – Includes both chronic major depressive disorder and dysthymic disorder. A persistent depressed mood for more of the day for more days than not, for at least one year, when symptom-free intervals last no longer than two consecutive months. *See "Depressive Disorders" section.* 

**pervasive developmental disorders (PDD)** – These disorders can usually be identified in the early years of a child's life. Children with PDD have difficulty in areas of development or use of functional skills such as language, communication, socialization, and motor behaviors. In May 2013, the American Psychiatric Association released the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition,* which recategorizes pervasive developmental disorders under the umbrella term "autism spectrum disorder." Research studies and clinicians may still use the term pervasive developmental disorders. *See "Autism Spectrum Disorder" section.* 

**pharmacology** – The study of the nature, actions, and uses of drugs.

**phobia** –An uncontrollable, irrational, and persistent fear of a specific object, situation, or activity. Also called "specific phobia." *See "Anxiety Disorders" section*.

**physiological response** – Related to the physical changes in the body that follow a stimulus.

**placebo** – A pharmacologically inert substance (such as saline solution or a starch tablet) that replaces pharmacologically active substance (such as an antibiotic). Placebos are usually used as part of a clinical trial or double-blind study to help measure if a particular drug outperforms the placebo. People can experience a reduction of symptoms or a measurable improvement in health after taking a placebo. This phenomenon is poorly understood and is referred to as the placebo effect.

**plan of care** – A treatment plan that identifies the child and family's strengths and needs, establishes goals, details appropriate treatment and services.

**positive behavior support** – Re-directive therapy used in the home or school environment that has the goal of helping the youth strengthen communication, social, and self-management skills.

**post-traumatic stress disorder (PTSD)** – A debilitating condition that often follows a terrifying physical or emotional event causing the person who survived the event to have persistent,

frightening thoughts and memories, or flashbacks, of the ordeal. Persons with PTSD often feel chronically, emotionally numb. *See "Trauma- and Stressor-Related Disorders" section*.

**practice guidelines** – Refers to the American Academy of Child and Adolescent Psychiatry (AACAP) practice guidelines that prescribe treatments and include resources and tools to assist practitioners and provide evidence-based recommendations for the assessment and treatment of psychiatric disorders.

**premonitory urge** – A term commonly used to describe early, minor symptoms that precede a major health problem.

**premorbid** – Preceding the occurrence of disease.

**prognosis** – The expected outcome or course of a disease, which includes the patient's chance of recovery.

**protective factor** – See risk and protective factors.

**prevalence** – The number of afflicted persons present at a particular time in relation to the size of the population.

**prevention services** – Services that promote families, communities, and systems working together to reduce the incidence of mental illness, mental retardation, other developmental disabilities, and substance abuse disorders. Emphasis is on the enhancement of protective factors and reduction of risk factors. Activities may include information dissemination, prevention education, and problem identification and referral. Services are most often provided by social service agencies, community services boards, pediatricians and nurses in health clinics, and schools.

**private inpatient units** – Privately-owned hospitals that offer inpatient psychiatric and/or substance abuse services to individuals with severe, acute disturbances. They are licensed as hospitals under state regulations.

**private providers** – Mental health professionals who provide services in private offices or within the context of private mental health centers. The services that they provide are not publicly-funded, and therefore treatments are usually paid for either through private insurance, Medicaid, or the FAMIS program, or through contracts with public agencies.

**private residential units** – Privately-owned residential facilities that provide intensive treatment services to children and adolescents with emotional or mental disorders. They are somewhat less restrictive than private inpatient units, but still tend to be highly structured and secure, and should be reserved for children and adolescents in crisis. However, the level of security and restrictiveness tend to vary across facilities.

**psychoeducational services** – The process of providing information to parents, children, and teachers about the features of the child's diagnosis, the most effective management strategies, and the services available to provide the necessary treatment.

psychological evaluation – A clinical examination conducted by a mental health professional that is used to determine the nature of a child's psychological difficulties. It often includes an analysis of components of the child's life such as his/her development, behavior, education, medical history, and family and social relationships. An evaluation usually requires several hours to complete and is often best performed over several sessions, including sessions for the child and parents separately and together. In addition, a full evaluation usually requires the collection of information from a variety of outside sources, such as the school, child's pediatrician, psychological testing, and social service agencies.

**psychopathology** – The science that studies mental disorders.

**psychopharmacology** – The use of medication to treat mental disorders. These medications work to control the symptoms of mental illness by correcting or compensating for some malfunction in the body. Medications do not cure mental illness; instead they reduce the burdensome effects.

**psychosis** – A disruption of thinking that impairs an individual's perception of reality. Psychosis is frequently associated with the diagnosis of schizophrenia.

**psychotic** – A person experiencing psychosis, or a break with reality. Although a person who is psychotic may also be agitated or aggressive, the term does not imply that the affected person is violent.

**psychosocial** – Involving aspects of social and psychological behavior.

**psychosocial treatments** – Services that focus on the relationship between psychological, environmental, and social factors. They include certain forms of psychotherapy as well as social and vocational training, and are intended to provide support, education, and guidance to people with mental illnesses and their families. A psychiatrist, psychologist, social worker, or counselor typically provides psychosocial treatments.

**psychostimulant** – See stimulants.

**psychotherapy** – An intervention that involves regularly scheduled sessions between a patient and a mental health professional, such as a psychiatrist, psychologist, psychiatric social worker, or psychiatric nurse. The goal of this treatment is to help patients understand why they are acting and thinking in ways that are troubling or dangerous to themselves or others so they have more control over their behaviors and can correct them. It is commonly used in the treatment of children and youth with emotional and behavioral problems, either in conjunction with or in place of prescribed medications. This form of therapy has many forms, such as psychodynamic, behavioral, cognitive-behavioral, interpersonal, supportive, and family systemic.

**psychotropic medications** – Prescribed drugs that reduce the symptoms of biologically based psychological disorders.

**purging** – A destructive pattern of ridding the body of excess calories (to control weight) by vomiting, abusing laxatives or diuretics, taking enemas, and/or exercising obsessively. Occurs

most frequently in individuals suffering from bulimia nervosa. See "Feeding and Eating Disorders" section.

**pyromaniac** – An individual having an irresistible impulse to start fires.

**randomized trial** – A type of clinical trial in which the participants are assigned randomly (by chance alone) to different treatments.

**rapid cycling** – The state of having had at least four manic, hypomanic, or major depressive bipolar mood episodes in the previous 12 months. Full or partial remissions must occur for at least two months between episodes unless there is a change in polarity (i.e. from a manic to a major depressive episode). *See "Bipolar and Related Disorders" section*.

**reactive attachment disorder** – A disorder characterized by serious problems in emotional attachments to others that usually presents by age five and that can be caused by trauma and/or neglect.

**regression** – A partial or symbolic return to earlier patterns of reacting or thinking.

**reinforcement** – The strengthening of a response by using a reward or a punishment. Reinforcement is central in operant conditioning.

**residential services** – Services that provide overnight care in conjunction with intensive treatment or training programs. They are typically provided in psychiatric hospitals, residential treatment centers (RTCs), and therapeutic foster homes.

residential treatment center (RTC) – 24-hour facilities providing short-term intermediate care, crisis stabilization, and intensive mental health treatment programs. They are not licensed as hospitals and serve as an alternative to inpatient psychiatric hospitalization. The settings vary, with some highly structured like psychiatric hospitals, while others are similar to group homes or halfway houses. They also vary in the range of services they offer, as some offer a full range of treatment services while others are more limited or specialized. While these facilities were originally designed to serve as long-stay institutions, under managed care they are serving youth for periods as brief as one month, serving only as a source for intensive evaluation and stabilization.

**respite care** – A type of family support service. Parents are given relief from childcare by either placing the child with another family or bringing a caretaker into the home for a few days. This service is usually provided on a planned basis under circumstances in which either there has been a prolonged crisis in which the child has exhausted the family resources, or there has been another family crisis, such as illness or death of another family member. This service may be provided by community services boards, social service agencies, or private clinics.

**risk and protective factors** – Factors that either increase or decrease an individual's likelihood of developing a disorder or disease. Risk and protective factors are determined through population studies. Exposure to risk or protective factors does not mean that any one individual will definitely contract or avoid contracting a particular disorder or disease.

**satiation** – The practice of repetitively lighting and extinguishing fire. *See "Juvenile Firesetting" section.* 

**schizoaffective disorder**– A mental health disorder characterized by recurring, alternating episodes of elevated or depressed moods with distorted perceptions.

**schizophrenia** – A severe, chronic, and disabling disturbance of the brain that causes distorted thinking, strange feelings, and unusual behavior and use of language and words. *See* "Schizophrenia" section.

**screening tool** – A brief assessment, which is valid and reliable, that is used to identify symptoms of a disorder or other problem.

**secure treatment service** – Provision of services for people with mental disorders or serious mental health problems who, based on clinical assessment, require treatment in a closed setting to ensure the safety of the person, the staff and the community. Three levels of treatment are provided" acute inpatient secure treatment, extended secure treatment and high security treatment.

**sedatives** – A group of drugs used to produce sedation (calmness). Sedatives include sleeping pills and anti-anxiety drugs.

**selective serotonin reuptake inhibitors** (**SSRIs**) – A class of drugs commonly prescribed for treating depression. SSRIs work by stopping brain receptor cells from absorbing serotonin, an action that allows more of this neurotransmitter to be available to be taken up by other cells. SSRIs can improve mood.

**self-help and support groups** – Groups designed for people and families dealing with life difficulties such as mental illness or substance abuse. Typically, they are not led by a professional therapist. However, these groups may be therapeutic because members give each other ongoing support and share experiences and coping mechanisms.

**self-harm or self-injury** – Also known as self-inflicted violence, self-injurious behavior or self-mutilation, self-harm is a deliberate, intentional injury to one's own body that causes tissue damage or leaves marks for more than a few minutes. Self-harm is often done to cope with an overwhelming or distressing situation. *See "Nonsuicidal Self Injury" section*.

**self-report measure** – When a person is asked to report his or her own behavior or mental state. Self-report measures can be formal assessment tools such as questionnaires.

**separation anxiety disorder (SAD)** – Excessive worry and fear about being apart from family members or individuals to whom a child is most attached. Children with separation anxiety disorder fear being lost from their family or fear something bad happening to a family member if they separated from them. *See "Anxiety Disorders" section*.

**serious emotional disturbance (SED)** – SED in children ages birth through 17 is defined as a serious mental health disorder that can be diagnosed using *DSM-5* criteria. Many of these disorders are discussed in the *Collection*.

**serotonin** – A neurotransmitter that is thought to affect mood and social behavior, appetite and digestion, sleep, memory, and sexual desire and function.

**serotonin and norepinephrine reuptake inhibitors (SNRIs)** – A class of drugs commonly prescribed for treating depression. SNRIs work by stopping brain receptor cells from absorbing both serotonin and norepinephrine, an action that allows more of these neurotransmitters to be available to be taken up by other cells and affects mood.

**social anxiety disorder** (**social phobia**) – Persistent anxiety out of proportion in either or both fear and duration to the situation in which the individual finds himself. Formerly "social phobia" in the *DSM-IV. See "Anxiety Disorders" section*.

**social history** – When children and adolescents become involved with the juvenile justice system, a social history is performed by personnel of the Court Service Unit. The social history describes the social adjustment of the person before the court, which is used to help the court to select the most appropriate disposition for the case. The social history is also used by the court service unit to develop appropriate services for the juvenile and the family. A social history may also be conducted by other health care providers for purposes of conducting a mental health evaluation.

**social modeling** – A tool that integrates the cognitive modeling approach (which stresses how beliefs are formed and drive behavior) with social studies (which stress how relationships and informal practices drive behavior). The intent of social modeling in treatment is to present positive models for change.

**somatization** – The process of experiencing mental and emotional stress in a way that manifests as physical symptoms (such as stomach aches or headaches).

**special education** – Specially designed instruction that adapts, as appropriate, to the needs of a disabled child. Such education must ensure access for the child to the general curriculum, so that he or she can meet the educational standards that apply to all children. This education is to be provided at no cost to the parents and is implemented under the guidelines of the Individuals with Disabilities Act (IDEA), which requires school to identify children with disabilities in need of special education.

**special education day schools** – A form of therapeutic day treatment. These are schools that are specially designed to meet the needs of children with severe behavior disorders who are unable to function adaptively in the regular school system. The programs allow for collaboration between teachers and mental health professionals, and provide low student-teacher ratios and additional family services with the ultimate goal of returning the child to the regular school setting.

**specific phobia** – See phobia.

**specifier** – A specifier or criteria is a specific symptom or characteristic used to diagnose a mental health disorder.

**spectrum** – A condition that is not limited to a specific set of values, but that can vary within a continuum.

**Standards of Learning (SOLs)** – The outline of the basic knowledge and skills that Virginia children will be taught in grades K-12 in the academic subjects of English, math, science, and social studies.

**state mental health facilities** – State-run facilities providing a range of psychiatric, psychological, rehabilitative, nursing, support, and other necessary services for children and adolescents with significant and acute psychiatric concerns. One facility in the Commonwealth is designated for children and adolescents: the Commonwealth Center for the Treatment of Children and Adolescents.

**stuttering** – Speech characterized by abnormal hesitations, prolongations, and repetitions that are developmentally inappropriate for the age or mental ability of the speaker.

**substance abuse medical detoxification** – A form of inpatient services in which doctors and other medical personnel use medication to eliminate or reduce effects of alcohol or other drugs in the patient's body. These services are available in local hospitals or other emergency care facilities.

suicidality – Suicidal thinking and behavior. See "Youth Suicide" section.

**suicidal behavior** – Actions taken by one who is considering or preparing to cause their own death. May include a suicide attempt, which is an act focused on taking one's life that is unsuccessful in causing death. *See "Youth Suicide" section.* 

**suicidal ideation** – Persistent thoughts of suicide or wanting to take one's life. *See "Youth Suicide" section.* 

suicide – The intentional taking of one's own life. See "Youth Suicide" section.

**supportive therapy** – Psychotherapy focusing on the management and resolution of current difficulties and life decisions using the individual's strengths and available resources.

**symptom** – A reported feeling or specific observable physical sign of a patient's condition that indicates a physical or mental abnormality.

**syndrome** – In most cases, the term refers to a grouping of signs and symptoms and not to the underlying disease or disorder that causes them.

**system of care** – A method of delivering mental health services that helps children and adolescents with mental health problems and their families get the full range of services in or near their homes and communities. These services must be tailored to each individual child's physical, emotional, social, and educational needs. In systems of care, local organizations work in teams to provide these services.

**tardive dyskinesia** – An involuntary movement disorder caused by the long-term use of antipsychotic drugs.

**Temporary Assistance for Needy Families (TANF)** – A block grant program designed to make welfare recipients self sufficient and turning welfare into a program of temporary assistance. TANF replaced the national welfare program known as Aid to Families with Dependent Children (AFDC) and the related programs known as the Job Opportunities and Basic Skills Training (JOBS) program and the Emergency Assistance (EA) program. TANF recipients are usually eligible for full Medicaid benefits and include children younger that 18 (or expected to graduate from high school by age 19). One of the child's parents must be dead, absent, disabled, or unemployed.

**The Arc** – A non-profit organization that supports persons with intellectual disability.

therapeutic camp services – A special form of therapeutic group care in which youth and staff live together in a wilderness environment. The nature of the living situation requires that participants demonstrate responsible and independent behavior in order to take care of the basic necessities of living, including food and shelter. The primary emphasis of the treatment is the encouragement of each participant to be a contributing member of the group. The goal of this form of treatment is to build skills in dealing with immediate situations of both a social and nonsocial nature.

therapeutic day treatment – An outpatient treatment program that serves children with diagnoses that range from severe emotional disturbance to developmental delay. These services provide an integrated set of psychoeducational activities, counseling, and family treatments that involve the young person for several hours each day. Services typically include special education, individual and group counseling, family counseling and training, crisis intervention, skill building, behavior modification, and recreational therapy. However, the nature of these programs may vary widely due to factors such as setting, the population being served, the intensity of treatment, the theoretical approach, and the treatment components. The integration of this broad range of services is designed to strengthen both individual and family functioning and to prevent a more restrictive placement of the child. The child is able to receive the benefits of a structured setting while being able to return home at night and continue involvement with family and peers. These services may be offered in regular school settings, special education day schools, community services boards, and hospitals. Currently, Medicaid is the only third party source that routinely covers this service.

therapeutic foster care — The least restrictive form of residential treatment, placing children in private homes with specially trained foster parents. It is typically provided to children and adolescents with emotional or behavioral disturbances. The intent of these programs is to provide treatment within a family context. Children are placed with foster parents who have been carefully selected to work with children with special needs. These parents receive education and training to assist in working effectively with the child, including topics such as active listening, behavioral management and programming, and age-appropriate behavioral expectations. These parents become part of a support structure that exists among the foster parents and case managers work in close connection with the child and family. During this placement, efforts are made to provide the biological family with counseling, support, and other types of assistance so that the

child can be returned to the home as quickly as possible. Programs tend to differ in approach, structure, intensity and type of training. Most serve youth from birth to 18 years, with most youth entering during early adolescence.

therapeutic group homes – Facilities that provide emotionally and behaviorally disturbed adolescents with an environment to learn social and psychological skills. These homes are located in the community, and residents attend the local schools. In Virginia, a group home is defined as a community-based, home-like single dwelling, or its acceptable equivalent, other than the private home of the operator, and serves up to 12 residents. An array of services is provided, such as individual psychotherapy, group therapy, and/or behavior modification. Vocational training and work experiences are typically included as part of the treatment program for adolescents. The amount of structure incorporated into the program varies based on the level of need of the youths served.

**therapeutic intervention** – Interventions based on an in-depth and extensive evaluation of the problem with clear and specific goals.

**tic disorder** – A type of motor disorder that may be classified as a vocal tic, a motor tic, a simple tic or a complex tic. A tic is an involuntary, sudden, rapid, recurrent, nonrhythmic motor movement or vocalization. *See "Motor Disorders" section*.

**Title IV-E** – The Federal Social Security Act authorizing financial assistance for foster children and for families receiving adoption assistance.

**Title V** – Title V of the Social Security Act, which became the Maternal and Child Health Services Block Grant in 1981.

**Title XVIII** – Social Security Act Pertaining to Medicare.

**Title XIX** – Medicaid. A federally aided, state-operated and administered program that provides medical benefits for certain indigent or low-income persons in need of health and medical care. Authorized by Title XIX of the Social Security Act.

**Title XXI** – The State Children's Health Insurance Program (SCHIP), part of the Social Security Act, that authorizes states to provide health insurance coverage to uninsured children up to 200% of the federal poverty level (FPL). States may provide this coverage by expanding Medicaid or by expanding or creating a state children's health insurance program. FAMIS is Virginia's SCHIP program.

**Tourette disorder** – A disorder characterized by multiple motor tics and at least one vocal tic. *See "Motor Disorders" section.* 

**transactional medical assistance** – Provides short-term Medicaid coverage for people who lose assistance when they secure a job that does not provide health benefits.

**transitional services** – Services that help children leave the system that provides help for children and move into adulthood and the adult service system. Help includes mental health care,

independent living services, supported housing, vocational services, and a range of other support services.

**trauma** – Any injury, physical or emotional. *See "Trauma- and Stressor-Related Disorders" section.* 

**trauma informed care** – Theory of care in which providers realize that trauma impacts children in a variety of ways, recognizes those signs in children and their families, and treats both the trauma and resulting symptoms in a way to prevent additional trauma to the individuals receiving care.

**traumatic event** – An occurrence that threatens injury, death, or the physical body or that causes emotional harm of a child or adolescent. Traumatic events often cause feelings of shock, terror, or helplessness.

**trichotillomania** (hair-pulling disorder) – A disorder wherein an individual pulls hairs from the body as a response to a stressor. *See "Obsessive-Compulsive and Related Disorders" section.* 

**tricyclic antidepressants** (**TCA**) – An older class of drugs used in the treatment of clinical depression and other disorders. Tricyclic refers to the presence of three rings in the chemical structure of these drugs.

**typology** – The study or systematic classification of types that have common characteristics or traits.

variability – Indicates there is a range of possible outcomes for a given situation.

**Virginia Independence Program (VIP)** – Virginia's welfare reform program.

**Virginia Initiative for Work not Welfare (VIEW)** – Work component of Temporary Assistance for Needy Families (TANF) program.

waiver – See Medicaid Waiver Program.

wraparound services – Child- and family-driven services and supports that are community-based. They address the child's needs in the home, school, and community, and are developed through collaboration between the child, family, and all of the service providers who provide support to the child. The underlying purpose is to provide services that follow the child as he/she interacts in different environments in the community. The organizations involved in collaboration can include mental health, education, juvenile justice, and child welfare. Case management is usually necessary to coordinate services.

# Commonly Used Acronyms and Abbreviations

AAA Area Agency on Aging

AACAP American Academy of Child & Adolescent Psychiatry

AAIDD American Association on Intellectual and Developmental Disabilities

AAP American Academy of Pediatrics

ABA Applied Behavior Analysis

ACT Assertive Community Treatment

AD Autistic Disorder

ADA American Dietetic Association or Americans with Disabilities Act

ADD Attention Deficit Disorder

ADDM Autism and Developmental Disabilities Monitoring

ADHD Attention-Deficit/Hyperactivity Disorder AFDC Aid to Families with Dependent Children

ALF Assisted Living Facility ALOS Average Length of Stay

AN Anorexia Nervosa

ANRED Anorexia Nervosa and Related Eating Disorders

APA American Psychiatric Association or American Psychological Association

Arc (The) formerly Association for Retarded Citizens

ART Aggression Replacement Therapy

AS Asperger's Disorder

ASAS Australian Scale for Asperger's Syndrome

ASD Autism Spectrum Disorder or Acute Stress Disorder

ASFA Adoption and Safe Families Act of 1997

ASQ Ages and Stages Questionnaire

AZT Azidothymidine

BCM Behavioral Classroom Management

BED Binge Eating Disorder BES Binge Eating Scale

BH-MCO Behavioral Health Managed Care Organization

BHA Behavioral Health Authority
BHO Behavioral Health Organization

BHRS Behavioral Health Rehabilitative Services

BIP Behavior Intervention Plan

BMI Body Mass Index

BN Bulimia Nervosa

BPD Borderline Personality Disorder or Bipolar Disorder

BPD-NOS Bipolar Disorder Not Otherwise Specified

BPI Behavioral Peer Intervention BPT Behavioral Parent Training

BT Behavioral Therapy
BULIT- R Bulimia Test-Revised

CAPS-CA Clinician-Administered PTSD Scale for Children and Adolescents

CASA Court Appointed Special Advocate

CBC Community-based Care

CBT Cognitive Behavioral Therapy

CD Conduct Disorder

CDC Centers for Disease Control and Prevention

CDIs Child Development Inventories
CFI Children's Firesetting Inventory

CHADD Children and Adults with Attention Deficit Disorders

CHAT Checklist for Autism in Toddlers

CHINS Child in Need of Services
CHINSup Child in Need of Supervision
CMHC Community Mental Health Center

CMS Centers for Medicare and Medicaid Services

COBRA Consolidated Omnibus Budget Reconciliation Act

COLA Cost of Living Adjustment
COS Childhood-onset Schizophrenia
COY Virginia Commission on Youth

CPMT Community Policy and Management Team (Virginia)

CPS Child Protective Services

CSA Children's Services Act for At Risk Youth and Families (Virginia)

CSAC Certified Substance Abuse Counselor
CSB Community Services Board (Virginia)

CSU Court Services Unit

CSOTP Certified Sex Offender Treatment Provider

CT Computer Tomography

DARE Drug Abuse Resistance Education

DARS Virginia Department of Aging and Rehabilitative Services

DBD Disruptive Behavioral Disorder

DBD-NOS Disruptive Behavioral Disorder Not Otherwise Specified

DBHDS Virginia Department of Behavioral Health and Developmental Services (formerly

DMHMRSAS)

DBT Dialectical Behavioral Therapy

DCE Virginia Department of Correctional Education
DCJS Virginia Department of Criminal Justice Services

DCSE Virginia Child Support Enforcement

DD Developmental Disability or Dually Diagnosed
DHP Virginia Department of Health Professions
DJJ Virginia Department of Juvenile Justice

DMAS Virginia Department of Medical Assistance Services

DMG Dimethylglycine

DOC Virginia Department of Corrections
DOE Virginia Department of Education

DRC Daily Report Card
DSH Deliberate Self-harm

DSM-IV-TR Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text

Revision

DSM-5 Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

DSS Virginia Department of Social Services

DTT Discrete Trial Teaching
DUI Driving Under the Influence

EA Emergency Assistance

EAP Employee Assistance Program

EAT Eating Attitudes Test

ECT Electroconvulsive Therapy
ED Emotional Disturbance

EDDS Eating Disorder Diagnostic Scale
EDE Eating Disorder Examination

EDED-Q Eating Disorder Examination Questionnaire

EDI-3 Eating Disorder Inventory - Revised

EDNOS Eating Disorders Not Otherwise Specified

EEG Electroencephalogram

EI Eating Inventory

EOS Early-onset Schizophrenia

EPSDT Early and Periodic Screening, Diagnosis, and Treatment

ERP Exposure and Response Prevention
ESL English as a Second Language

FAMIS Family Access and Medical Insurance Security Plan, Virginia's Title XXI Plan

FAMIS CPU Application-processing unit for FAMIS (Virginia)

FAPE Free Appropriate Public Education FAPT Family Assessment and Planning Team

FAS Fetal Alcohol Syndrome

FBI Federal Bureau of Investigation

FC Foster Care

FCT Family Centered Treatment FDA Food and Drug Administration

FEMA Federal Emergency Management Agency

FFT Functional Family Therapy

FIA-C Fire Incident Analysis for Children FIA-P Fire Incident Analysis for Parents

FPL Federal Poverty Level
FRI Firesetting Risk Inventory
GAD Generalized Anxiety Disorder

HRT Habit Reversal Therapy

HCBS Home and Community Based Services

HIPAA Health Insurance Portability and Accountability Act

HMO Health Maintenance Organization

I&R Information and ReferralICF Intermediate Care Facility

ICPC Interstate Compact for the Placement of Children

ICM Intensive Case Manager

ICPC Interstate Compact for the Placement of Children

ID Intellectual Disability

IDEA Individuals with Disabilities Education Act or Interview for the Diagnosis of

**Eating Disorders** 

IEP Individualized Educational Program
IFSP Individualized Family Service Plan

IOP Intensive Outpatient Therapy
IPT Interpersonal Psychotherapy

IQ Intelligence Quotient

ISP Individualized Service Plan
IVIG Intravenous Immunoglobulin
JCC Juvenile Correctional Center
JCHC Joint Commission on Health Care

JFNAP Juvenile Firesetter Needs Assessment Protocol
JLARC Joint Legislative Audit and Review Commission

LCSW Licensed Clinical Social Worker

LEAP Learning Experiences: an Alternative Program

LPC Licensed Professional Counselor

M-CHAT Modified Checklist for autism in Toddlers

MAEDS Multiaxial Assessment of Eating Disorder Symptoms

MDD Major Depressive Disorder MCO Managed Care Organization MDD Major Depressive Disorder

MDFT Multidimensional Family Therapy

MH Mental Health

MHA Mental Health America MI Medically Indigent

MMR Measles-Mumps-Rubella
MRI Magnetic Resonance Imaging

MSW Master of Social Work
MST Multisystemic Therapy

MTFC Multidimensional Treatment Foster Care
NAMI National Alliance for the Mentally Ill

NCLB No Child Left Behind

NCMHJJ National Center for Mental Health and Juvenile Justice

NCSBY National Center on Sexual Behavior of Youth NCTSN National Child Traumatic Stress Network

NES Night Eating Syndrome

NICHCY National Dissemination Center for Children with Disabilities

NIDA National Institute of Drug Abuse NIMH National Institute of Mental Health

NOS Not Otherwise Specified

NSIB Nonsuicidal Self-Injurious Behavior
OCD Obsessive-compulsive Disorder
ODD Oppositional Defiant Disorder

OJJDP Office of Juvenile Justice and Delinquency Prevention

PACCT Parents and Children Coping Together

PACT Program of Assertive Community Treatment

PBD Pediatric Bipolar Disorder

PAIMI Protection and Advocacy for Individuals with Mental Illnesses Act
Part C Part C of the Individuals with Disabilities Education Act (IDEA)

PCP Primary Care Provider

PCPID President's Committee for People with Intellectual Disabilities

PDD Pervasive Developmental Disorder

PDDST-II Pervasive Developmental Disorder Screening Test-II
PEATC Parent Educational Advocacy Training Center (Virginia)

PECS Picture Exchange Communication System
PEDS Parents Evaluation of Developmental Status

PMT Parent Management Training

POS Point of Service

PPO Preferred Provider Organization
PRT Pivotal Response Training

PTSD Posttraumatic Stress Disorder

PRWORA Personal Responsibility and Work Intermediate Care Facility for persons with

Opportunity Reconciliation Act of 1996

PITS Psychiatric Institute Trichotillomania Scale

RAD Reactive Attachment Disorder of Infancy or Early Childhood

RCF Residential Care Facility

RDI Relationship Development Intervention

RTC Residential Treatment Center
SAD Separation Anxiety Disorder
SAM Society for Adolescent Medicine

SAMHSA Substance Abuse and Mental Health Services Administration

SCHIP The State Children's Health Insurance Program, Title XXI of the Social Security

Act

SED Serious Emotional Disturbance
SEDS Stirling Eating Disorder Scale
SI Self-injury or Sensory Integration

SNAP Supplemental Nutrition Assistance Program

SOC Systems of Care

SOLs Standards of Learning

SP Skin Picking
SP Specific Phobias
SPED Special Education

SRED Sleep-related Eating Disorders
SRIs Serotonin Reuptake Inhibitors

VDARS Virginia Department of Aging and Rehabilitative Services

VDBHDS Virginia Department of Behavioral Health and Developmental Services (formerly

DMHMRSAS)

VDCE Virginia Department of Correctional Education VDCJS Virginia Department of Criminal Justice Services

VDCSE Virginia Child Support Enforcement

VDHP Virginia Department of Health Professions VDJJ Virginia Department of Juvenile Justice

VDMAS Virginia Department of Medical Assistance Services

VDOC Virginia Department of CorrectionsVDOE Virginia Department of EducationVDSS Virginia Department of Social Services

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# **SENATE JOINT RESOLUTION NO. 99, 2002**

Directing the Virginia Commission on Youth, or its successor in interest, to coordinate the collection and dissemination of empirically-based information on treatment modalities and practices recognized as effective for the treatment of children, including juvenile offenders, with mental health treatment needs, symptoms and disorders.

WHEREAS, each year the Commonwealth of Virginia and its localities, through the Comprehensive Services Act for At-Risk Youth and Families (CSA), spend millions of dollars to purchase services to address the emotional and behavioral problems of children and youth in Virginia; and

WHEREAS, there is no system in the Commonwealth to measure the quality or effectiveness of care received by these children and youth; and

WHEREAS, the Joint Legislative Audit and Review Commission, in its Review of the Comprehensive Services Act, Senate Document No. 26 (1998), reported that linking program and participant outcomes could provide "a meaningful tool to assess whether providers are producing the type of results required given the nature of the children they receive"; and

WHEREAS, with the exception of composite data that are reflected on the Office of Comprehensive Services' web site, which includes elements such as demographics, referral source, expenditures and number of children served through the Family Assessment and Planning Team (FAPT) process, data on individual children are not collected; and

WHEREAS, professionals and communities could benefit from information on treatment modalities and practices recognized as effective for the treatment of children with mental health treatment needs, symptoms and disorders; and

WHEREAS, to collect information on outcomes requires the development of an extensive and integrated information management system and longitudinal data collection, both of which require considerable resources; and

WHEREAS, the collection of empirically sound research on the treatment modalities and practices that have proven most effective for children and adolescents would serve as the initial step in evaluation efforts: and

WHEREAS, this research as collected could be used as a foundation for the future collection of client-specific information; and

WHEREAS, such information could be shared with entities involved in efforts to develop a policy and plan for children's improved access to mental health services, including the identification of effective models for replication; now, therefore, be it

RESOLVED by the Senate, the House of Delegates concurring, That the Virginia Commission on Youth, or its successor in interest, be directed to coordinate the collection and dissemination of empirically-based information on treatment modalities and practices recognized as effective for the treatment of children, including juvenile offenders, with mental health treatment needs, symptoms and disorders.

An advisory committee comprised of state and local representatives from the Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services, Virginia Department of Social Services, Virginia Department of Medical Assistance Services, Virginia Department of Juvenile Justice, Virginia Department of Education, Virginia Department of Health, Virginia Office of Comprehensive Services, private providers and parent representatives shall assist and guide the effort of the entity directed to collect and disseminate the aforementioned information. All agencies of the Commonwealth shall provide assistance to the entity directed to collect and disseminate such information, upon request.

The Virginia Commission on Youth, or its successor in interest, shall submit a copy of the information directed to be collected and disseminated concerning effective treatment modalities and practices for treating children, including juvenile offenders, with mental health treatment needs, symptoms, and disorders to the General Assembly through the Senate Committee on Education and Health, the Senate Committee on Rehabilitation and Social Services, the House Committee on Health, Welfare and Institutions, and to the Division of Legislative Services, no later than November 30, 2002.

# **SENATE JOINT RESOLUTION NO. 358, 2003**

Directing the Virginia Commission on Youth, or its successor in interest, to make empirically based information concerning effective treatment modalities and practices for children available through the Internet.

WHEREAS, upon the recommendations of the Virginia Commission on Youth's Study of Children and Youth with Serious Emotional Disturbances Requiring Out-of-Home Placement, House Joint Resolution No. 119 (2000), and the Committee Studying Treatment Options for Offenders with Mental Illness or Substance Abuse Disorders, Senate Joint Resolution No. 440 (2001), the Virginia Commission on Youth was directed to study treatment options for offenders with mental illness or substance abuse disorders, pursuant to Senate Joint Resolution No. 99 (2002); and

WHEREAS, Senate Joint Resolution No. 99 (2002) also directed the Virginia Commission on Youth to coordinate the collection and dissemination of empirically based information that identifies effective treatment modalities and practices for children, including juvenile offenders with mental health treatment needs, symptoms, and disorders; and

WHEREAS, to accomplish its work, the Commission appointed representatives to a special study committee, the SJR 99 Advisory Group, to study effective treatment modalities for children with mental disorders, and the Advisory Group met four times to receive public comment from consumers, family members, advocates, criminal justice professionals, treatment providers, academic faculty, and other experts; and

WHEREAS, in addition to the SJR 99 Advisory Group, the Commission convened a smaller clinical group, which met seven times to provide specialized expertise and guidance on the substantive aspects of the collection of evidence based treatment modalities for children and adolescents with mental health treatment needs; and

WHEREAS, the members of the SJR 99 Advisory Group and Clinical Group have acquired considerable expertise in the treatment needs of children with mental health disorders, and noted that nationally and in Virginia, increased attention has been given to children's mental health and the development of systems of care for children with serious emotional disorders; and

WHEREAS, family members, practitioners, and researchers have become increasingly aware that mental health services are an important and necessary support for young children and their families who experience mental, emotional, or behavioral challenges; and

WHEREAS, child and adolescent mental health has emerged as a distinct area for service delivery, drawing on the philosophies and practices that characterize other childhood fields, such as early intervention; and

WHEREAS, according to estimates by the Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services, each year more than 75,000 children experience the disabling symptoms of serious mental illness or emotional disturbance; and

WHEREAS, there has been a mounting interest in evaluating and developing empirically supported treatments for children in response to the noted prevalence of these problems with children; and

WHEREAS, the Commonwealth and its localities spend a substantial amount of money each year to provide mental health and substance abuse treatment services to children and adolescents, and the lack of information regarding the effectiveness of such services results in failed treatments and wasted resources: and

WHEREAS, over the past 30 years, there has been a movement calling for improvement in the "quality of evidence" in studies that claim to benefit children; and

WHEREAS, current emphasis on evidence-based practices for mental health treatments indicates that such practices promote effective use of resources, improve the clinician's knowledge, and allow for the identification of health care methods that have been evaluated for effectiveness; and

WHEREAS, increased awareness of mental health issues, the demand for the best medical treatment at affordable prices, and emphasis on evidence based practices are reasonable and justifiable consumer responses that may provide cost savings; now, therefore, be it

RESOLVED by the Senate, the House of Delegates concurring, That the Virginia Commission on Youth, or its successor in interest, be directed to make empirically based information concerning effective treatment modalities and practices for children available through the Internet. The Commission shall seek the assistance of the SJR 99

Advisory Group, the Secretary of Health and Human Resources, the Secretary of Public Safety, and the Secretary of Education in posting, maintaining, and biennially updating this information. Such information shall include effective, empirically based, treatment modalities and practices for children, including juvenile offenders with mental health treatment needs, symptoms, and disorders; and, be it

RESOLVED FURTHER, That agencies of the Secretariat of Health and Human Resources that deliver services to children, the Department of Education, and the Department of Juvenile Justice shall also post this information on their respective websites, provide for the dissemination of the information in as efficient and cost-effective manner as possible, and ensure access to the information by consumers, family members, advocates, mental health policy makers, and other interested persons.

The Virginia Commission on Youth, or its successor in interest, shall submit to the Division of Legislative Automated Systems an executive summary and report of its progress in meeting the directives of this resolution no later than the first day of the 2004 Regular Session of the General Assembly. The executive summary and report shall be submitted as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents and reports and shall be posted on the General Assembly's website.