REPORT OF THE
VIRGINIA DEPARTMENT OF EDUCATION

Services Available for Individuals with Autism and Pervasive Developmental Disorders

TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA

HOUSE DOCUMENT NO. 21

COMMONWEALTH OF VIRGINIA
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COMMONWEALTH *of* VIRGINIA

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December 19, 2001

The Honorable James S. Gilmore, III, Governor
Members of the General Assembly of Virginia
State Capitol Building
Richmond, Virginia 23219

Dear Governor Gilmore and Members of the 2002 General Assembly:

I am pleased to transmit *Services Available for Individuals with Autism and Pervasive Developmental Disorders*, prepared by the Virginia Institute for Developmental Disabilities, Virginia Commonwealth University, pursuant to House Joint Resolution (HJR) 228 of the 2000 General Assembly and HJR 523 of the 2001 General Assembly. These resolutions requested the Department of Education as lead agency, the Department of Health, and the Department of Mental Health, Mental Retardation, and Substance Abuse Services to study the services available for individuals with autism and pervasive developmental disorders.

If you have questions or require additional information relative to this transmittal, please do not hesitate to contact me or Mr. H. Douglas Cox, assistant superintendent for instructional support services at (804) 225-3252.

Sincerely,

Jo Lynne DeMary

Jo Lynne DeMary

JLD/hdc

Attachment

cc: The Honorable Cherie P. Yecke

Preface

House Joint Resolution (HJR) 228, offered January 24, 2000, requested the Virginia Departments of Education, Health, and Mental Health, Mental Retardation, and Substance Abuse Services to study the services available for children with autism and pervasive developmental disorders. Patrons of this study include Thomas, Clement, Hall, Hamilton, Plum, Robinson, Van Landingham, and Woodrum.

The Virginia Department of Education (VDOE) served as the lead agency for HJR 228. VDOE contracted with the Virginia Institute for Developmental Disabilities (VIDD) at Virginia Commonwealth University (VCU) to complete the study. Individuals at VIDD who were responsible for this study included Stacy Dymond, Study Director; Steve Myran, Evaluation Specialist; and Gordon Myers, Research Assistant.

A Study Group was formed to guide the overall design and implementation of the study. This group consisted of six members representing four agencies. Members included:

Patricia Abrams, Virginia Department of Education
Nancy Bullock, Virginia Department of Health
H. Douglas Cox, Virginia Department of Education
Heidi Lawyer, Department for Rights of Virginians with Disabilities
Shirley Ricks, Department of Mental Health, Mental Retardation,
    and Substance Abuse Services
Sharon Siler, Virginia Department of Education

In addition, an Advisory Panel of key stakeholders with expertise in autism spectrum disorders was formed to provide input to the study's design, review and provide feedback on the instrumentation, and offer interpretations and recommendations based on the study's findings. The Advisory Panel included membership from a variety of stakeholder groups (i.e., parents, school personnel, technical assistance providers, medical treatment providers, community services board staff, early intervention providers, disability organizations) representing each of the diverse regions of the state. A list of the Advisory Panel members, their affiliations, and the regions of the state they represent is provided in Appendix B.

In addition to the Study Group and Advisory Panel members, VIDD would like to acknowledge the contributions of several individuals who assisted with this study. Jane Kroboth, from The Autism Program of Virginia, provided invaluable technical assistance to VIDD throughout the study's duration. Special thanks are also extended to Leeann Campbell, Leslie Daniel, Sharon Jones, Mehdi Mansouri, Linda Oggel, Paul Robertson, Carol Schall, and Jim Yucha for their assistance.

Stacy Dymond and Steve Myran completed technical writing for this report.

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Executive Summary

HJR 228 requested the Virginia Departments of Education, Health, and Mental Health, Mental Retardation, and Substance Abuse Services to study the services available for children with autism and pervasive developmental disorders (henceforth referred to as "children with autism spectrum disorders"). As lead agency responsible for the study, the Virginia Department of Education (VDOE) contracted with the Virginia Institute for Developmental Disabilities (VIDD) at Virginia Commonwealth University (VCU) to complete the study. The study commenced October 1, 2000 and concluded July 31, 2001.

A Study Group composed of representatives from four state agencies was formed to guide the overall design and implementation of the study. An Advisory Panel was also created to provide input to the study's design, review and provide feedback on the instrumentation, and offer interpretations and recommendations based on the study's findings. The panel included membership from a variety of stakeholder groups (i.e., parents, school personnel, technical assistance providers, medical treatment providers, community services board staff, early intervention providers, disability organizations) representing the diverse regions of the state.

Data were gathered through surveys, group discussions, focus groups, informal interviews, existing databases, and a review of the research literature. All procedures and instrumentation used in this study were approved by the VCU Institutional Review Board (IRB) and by VDOE. The design of the study sought to obtain input from multiple stakeholder groups, including parents of children with autism spectrum disorders, special education teachers, related services personnel (e.g., speech and language therapists, behavior therapists, psychologists), special education administrators, treatment providers (i.e., individuals who provide services outside the school setting), Local Interagency Coordinating Council (LICC) coordinators, Community Services Board (CSB) mental retardation (MR) directors, statewide technical assistance providers (i.e., The Autism Program of Virginia, Training and Technical Assistance Centers, Virginia Autism Resource Center), the Advisory Panel, and the Study Group.

Study Area 1: The Characteristics, Number, and Location Of Children with Autism Spectrum Disorders

The Virginia Department of Education (VDOE) is the only agency that is mandated to collect information about the number and location of children with autism spectrum disorders in Virginia. These data are limited to children between the ages of 3 and 22. While information is available about the number and location of children with disabilities between birth and age two, these data do not specifically identify children with autism spectrum disorders. In addition, no agency is required to maintain records on the characteristics (e.g., type of autism spectrum disorder, presence of other disabilities) of children with autism spectrum disorders.

Existing data from VDOE indicate steady growth in the number of children with autism spectrum disorders over the last decade. Most children who are identified with an autism spectrum disorder are elementary school-aged and are spending less that 60% of their day in the general education classroom. Overall, there appears to be a need for a comprehensive strategy for tracking the number, location, and characteristics of children with autism spectrum disorders in Virginia.

Study Area 2: The Availability of Teachers and Other Special Education and Treatment Professionals

Survey respondents indicated that the availability of teachers and other special education and treatment professionals for children with autism spectrum disorders vary widely across Virginia. Although most parents were able to obtain an initial diagnosis of autism spectrum disorders from a professional within their locality, the majority experienced difficulty locating service providers following their child's diagnosis. This challenge in locating qualified personnel was acknowledged by special education administrators, LICC coordinators, and MR directors. Inadequate numbers of professionals exist to serve children with autism spectrum disorders in many areas of Virginia.

Despite difficulties with sustaining sufficient numbers of qualified professionals, most direct service providers (special education teachers, related services personnel, treatment providers) indicated that they have access to other professionals in their school/office who have expertise in the area of autism. Although the number of professionals available to provide services to children with autism spectrum disorders appears limited, those professionals who are employed in this capacity frequently have access to other service providers with similar expertise in their locality.

Study Area 3: The Level of Expertise Found in the Various Areas of Virginia

The findings from Study Area 3 suggest that the level of expertise of professionals working with children with autism spectrum disorders is questionable. Substantial numbers of professionals (somewhat less than 50% across stakeholder groups) reported that they questioned their training and qualifications to work with children with autism spectrum disorders, as well as their knowledge about educational and medical approaches for working with this population. On the whole, a majority of respondents within each stakeholder group reported that they had adequate training in their specific area of endorsement/expertise, but had less confidence in their training specifically for teaching/serving children with autism spectrum disorders. Few professionals indicated that they received adequate preparation to teach children with autism during their preservice training program and many indicated limited satisfaction with both their access to inservice training and the usefulness of the training they received.

Study Area 4: The Adequacy of the Available Services for Children with Autism Spectrum Disorders

Taken together the data collected among the various stakeholder groups suggest that there is a good deal of variability in the adequacy of available services for children with autism. While these data do not suggest a clearly positive or negative atmosphere in the state regarding the adequacy of the available services, substantial portions of the various stakeholder groups reported a lack of adequacy of available services. For example, just over half the special education administrators surveyed reported that parents of children with autism spectrum disorders have requested services that their school division/program was unable or chose not to provide. Only little better than half of special education teachers, related service personnel, and special education administrators agreed that children with autism spectrum disorders receive the types and amount of services they need at school. Lastly a large majority of special education teachers, special education administrators, and related services personnel indicated that general education classrooms are not staffed appropriately to meet the needs of children with autism spectrum disorders. Parents' responses to all of these questions varied tremendously. Somewhat higher ratings were given regarding the staffing of special education classrooms. In summary, these data show wide variability in responses, possibly indicating a variation among schools, school divisions, and geographic regions of the state. Other variability may be due to age of the child and the disability level (i.e., mild or severe).

Study Area 5: The Efficacy of the Various Treatment Approaches

Preliminary findings suggest that few approaches offer substantial empirical evidence to support their effectiveness. Of the approaches reviewed, applied behavior analysis provided the most substantial number of empirically based studies. The benefits of early intervention, positive behavior supports, and augmentative communication were also well documented. For two of the approaches, chelation therapy and SCERTS (Social Communication Emotional Regulation and Transactional Supports), no literature was located to indicate that the approach had been scientifically investigated. Most other approaches were supported by a limited amount of research. In some cases the approach (e.g., inclusive education) had been extensively researched but information on its specific benefits for children with autism was limited. Controversial approaches identified in the literature include auditory integration training, facilitated communication, and secretin. Given the current debate surrounding the efficacy of practices for educating children with autism, researchers are increasingly supporting the use of multiple educational approaches that are based on the individual needs of the child (Heflin & Simpson, 1998; Smith, 2001). Additional research is needed to extend our understanding of the effectiveness of all approaches for children who fall across the autism spectrum.

Surveys conducted with parents, special education teachers, related services personnel, and treatment providers (i.e., non-school professionals) in Virginia provided an array of perceptions regarding the efficacy of the approaches studied. All of the 20 approaches were perceived to be effective by at least some of the respondents. Since these data rely on perceptions rather than empirical evidence, they provide valid information about the experiences of stakeholders in Virginia but not about the efficacy of the approaches. Data from these surveys support the need for multiple approaches and the selection of approaches based on the individual needs of the child.

Challenges in Serving Children with Autism Spectrum Disorders

Professionals identified several challenges in providing services for children with autism spectrum disorders. Although many of the themes that emerged were similar across stakeholder groups, the relative emphasis placed on each theme varied considerably among groups. The one challenge that all groups cited as a primary challenge was a "lack of information, trained teachers/professionals, services, resources, and time." The overall themes that emerged clustered around the following challenges:

- Lack of information, trained teachers/professionals, services, resources, and time
- Meeting diverse student needs
- Coordination of services and cooperation among professionals
- Lack of knowledge about autism
- Negative attitudes and conflicting expectations
- Obtaining an accurate diagnosis
- Funding streams that do not cover autism
- Providing/funding the intensity of services requested
- Determining effective approaches

Strategies for Improving Services in Virginia

Parents and professionals were asked to identify steps that could be taken by the Commonwealth of Virginia to improve services for children with autism spectrum disorders. Toward the conclusion of the study, members of the HJR 228 Advisory Panel and Study Group met to review the preliminary recommendations generated across all stakeholder groups and to identify those stakeholder recommendations that they believed would make the most significant impact on improving services for children with autism spectrum disorders in Virginia. These recommendations are listed below.

- Provide more training for individuals working with children with autism spectrum disorders. This training should promote eclectic, research-based approaches that reflect best practices. Educate parents about the various treatment approaches, services, and resources available.

- Across all disciplines, provide university course work that addresses the needs of children with autism spectrum disorders. Professionals should be adequately prepared to work with this population upon exiting their preservice training program.

- Train treatment providers to accurately diagnose children with autism spectrum disorders. These providers should possess the skills to identify children at a young age so that children can receive appropriate early intervention services.

- Make community services (i.e., those not provided by the school) more available, accessible, and equitable across the state. Disseminate information about these services.

- Require insurance companies to cover services, therapies, and treatments for children with autism spectrum disorders.

Definition of Autism Spectrum Disorders

The terms "autism", "autism spectrum disorders", and "pervasive developmental disorders" are frequently used interchangeably in the literature. They refer to a category of disabilities that are characterized by impairments in social interaction skills, communication skills, and behavior. For some children, the disability may have a relatively mild impact on day-to-day functioning, whereas other children may experience a severe disability that requires intensive supports. In this report, the term "autism spectrum disorders" is used because it emphasizes the wide range of skills, abilities, and manifestations of the disability.

Although there are many descriptions of autism spectrum disorders, the HJR 228 Advisory Panel reported that the most comprehensive definitions of the disability are published through 1) the Autism Society of America, 2) the Diagnostic and Statistical Manual of Mental Disorders (2000), and 3) the Individuals with Disabilities Education Act (1997). The Advisory Panel felt that any one of these definitions in isolation was insufficient. When viewed as a whole, they provide a thorough description of the disability. These definitions provide the necessary context for understanding the findings from the HJR 228 study.

Autism Society of America

"Autism is a complex developmental disability that typically appears during the first three years of life. The result of a neurological disorder that affects the functioning of the brain, autism and its associated behaviors have been estimated to occur in as many as 1 in 500 individuals (Centers for Disease Control and Prevention 1997). Autism is four times more prevalent in boys than girls and knows no racial, ethnic, or social boundaries. Family income, lifestyle, and educational levels do not affect the chance of autism's occurrence.

"Autism impacts the normal development of the brain in the areas of social interaction and communication skills. Children and adults with autism typically have difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities. The disorder makes it hard for them to communicate with others and relate to the outside world. In some cases, aggressive and/or self-injurious behavior may be present. Persons with autism may exhibit repeated body movements (hand flapping, rocking), unusual responses to people or attachments to objects and resistance to changes in routines. Individuals may also experience sensitivities in the five senses of sight, hearing, touch, smell, and taste.

"Over one half million people in the U.S. today have autism or some form of pervasive developmental disorder. Its prevalence rate makes autism one of the most common developmental disabilities. Yet most of the public, including many professionals in the medical, educational, and vocational fields, are still unaware of how autism affects people and how they can effectively work with individuals with autism."

Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)

The DSM-IV manual, published by the American Psychological Association (2000), uses the term "pervasive developmental disorders" (PDD) to describe a number of distinct diagnoses specific to the spectrum of autism. These diagnoses include:

- Autistic Disorder
- Rett's Disorder
- Childhood Disintegrative Disorder
- Asperger's Disorder
- Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)

Autistic disorder is noted as the most prevalent form of PDD. According to the DSM-IV manual (2000), autistic disorder may be defined as:

- "qualitative impairment in social interaction
- qualitative impairments in communication
- restricted repetitive and stereotyped patterns of behavior, interests, and activities
- delays or abnormal functioning in at least one of the following areas, with onset prior to 3 years: social interaction, language as used in social communication, or symbolic or imaginative play
- the disturbance is better not accounted for by Rett's Disorder or Childhood Disintegrative Disorder" (p. 75)

Individuals with Disabilities Education Act (1997) §300.7(c)(1)

(i) Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance.

(ii) A child who manifests the characteristics of "autism" after age 3 could be diagnosed as having "autism" if the criteria in paragraph (i) of this section are satisfied.

Study Methodology

The Virginia Department of Education (VDOE); the Virginia Department of Health (VDH); and the Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services (DMHMRSAS) were requested through HJR 228 to study the services available for children with autism spectrum disorders in Virginia. As lead agency for HJR 228, VDOE contracted with the Virginia Institute for Developmental Disabilities (VIDD) at Virginia Commonwealth University (VCU) to conduct the study. VIDD developed the evaluation design, coordinated meetings with the Study Group and Advisory Panel, designed instrumentation, collected and analyzed data, and developed the final study report. Work on the study commenced October 1, 2000 and concluded July 30, 2001. A copy of HJR 228 is provided in Appendix A.

Management of the Study

VIDD received assistance with the HJR 228 study from three groups. First, a Study Group was formed to guide the overall design and implementation of the study. Membership on the committee consisted of representatives from VDOE, VDH, DMHMRSAS, and the Department for Rights of Virginians with Disabilities (DRVD). A list of the Study Group members is provided in the preface of this report. This group met face-to-face twice during the study and communicated regularly through telephone and email.

Second, an Advisory Panel of key stakeholders with expertise in autism spectrum disorders was formed to provide input to the study's design, review and provide feedback on the instrumentation, and offer interpretations and recommendations based on the study's findings. The Advisory Panel included membership from a variety of stakeholder groups (i.e., parents, school personnel, technical assistance providers, medical treatment providers, community services board staff, early intervention providers, disability organizations) representing each of the diverse regions of the state. A list of the Advisory Panel members, their affiliations, and the regions of the state they represent is provided in Appendix B. The panel met face-to-face twice during the study period for full day meetings. Additional input was solicited from panel members via email. Study Group members attended both Advisory Panel meetings.

Finally, the Autism Program of Virginia (TAP-VA) provided technical assistance to VIDD throughout the study's duration. This assistance consisted of participating on the Advisory Panel and in focus group discussions, providing literature on autism spectrum disorders, identifying treatment providers to participate in the study, disseminating information about the study to potential study participants, and communicating essential information in response to questions posed by VIDD's project staff.

Sources of Data

Data were collected through surveys, group discussions, focus groups, informal interviews, existing databases, and a review of the research literature. A description of the specific methods used to address each study question is provided within each subsequent chapter (see the "overview" sections).

All procedures and instrumentation used in this study were approved by the VCU Institutional Review Board (IRB) and by the Virginia Department of Education. Participation in the study was voluntary and no identifying information was recorded that would allow the staff to track responses back to specific individuals.

Surveys

Seven surveys were conducted to obtain the perceptions of parents of children with autism spectrum disorders, special education teachers, related services personnel (e.g., speech and language pathologists, occupational therapists, school psychologists), special education administrators, treatment providers (i.e., professionals who serve children with autism spectrum disorders outside the school setting), Local Interagency Coordinating Council (LICC) coordinators, and mental retardation (MR) directors at the Community Services Boards (CSBs). Four of the seven surveys were offered on the Internet. Special education administrators, special education teachers, related services personnel, and treatment providers received a letter providing information about the survey and requesting their participation. Individuals wishing to participate logged onto the website, entered their survey responses, and submitted their completed survey electronically. Those who did not want to complete the survey via the Internet were mailed a paper copy of the survey. Parents, LICC coordinators, and MR directors were provided a paper survey to complete along with a postage paid envelope in which to return the survey upon completion.

According to Table 2.1, a total of 847 surveys were obtained from parents of children with autism spectrum disorders. Note that these respondents are grouped according to eight Superintendent's Regions. Each Superintendent's Region represents a particular geographic area of the state (see Appendix C for a list of the school divisions in each region). While there is representation from each region, Advisory Panel members who reviewed these data expressed concern about the large number of respondents from region 4 (i.e., northern Virginia). They suggested that caution be exercised in interpreting the data from parents, because the experiences and views of parents in northern Virginia may not be representative of parents living in other areas of the state.

The Advisory Panel also questioned whether all parents of children with autism spectrum disorders had been given an opportunity to participate in the survey. Surveys were distributed to the directors of special education in each school division, regional special education program, private day school, and private residential school based on the number of children with autism spectrum disorders they reported to VDOE for the December 1, 2000 child count. These directors were requested to distribute the surveys to special education teachers with written instructions (provided by VIDD) to send a copy of the survey home with each child they served who had autism spectrum disorders. Parents received the survey in a sealed envelope along with a cover letter explaining the survey and a postage paid reply envelope. Additional surveys were mailed to school administrators as requested. This process for disseminating the surveys was discussed and supported by both the Study Group and members of the State Council of Special Education Directors as the best method for reaching parents given the lack of a reliable database containing parent names and addresses.

Table 2.1
Number of Parent Survey Respondents By Superintendent's Region

Superintendent's Region	Number	Percent
1	118	13.9%
2	179	21.1%
3	44	5.2%
4	355	41.9%
5	60	7.1%
6	47	5.5%
7	18	2.1%
8	6	.7%
Missing Data*	20	2.4%
Total	847	100%

*Respondents did not provide information regarding the geographic location where they live.

Several steps were taken to maximize the response rate from parents. First, information about the surveys was distributed to each Autism Society of America chapter, The Autism Program of Virginia, the Virginia Autism Resource Center, and the Training and Technical Assistance Centers. These organizations were requested to inform parents about the survey and encourage their participation. Several organizations contacted people by mail or email to spread the word about the surveys. Second, special education directors received a postcard reminder in the mail asking them to remind their teachers to encourage parent participation. The need for reminding special education teachers was also discussed by VDOE staff with directors at their regional meetings and at a State Council meeting. Third, since some parents did not receive their survey until late, the deadline for receiving completed surveys was extended from May 11 to June 15 (an extension of 5 weeks). While these steps were designed to ensure all parents had an opportunity to participate, discussions with members of the Advisory Board and with parents who contacted the study director suggest that some parents experienced difficulty obtaining a survey or did not receive information about the study.

Special education directors were also instructed to disseminate survey information (provided by VIDD) to all special education teachers and related services personnel who worked with children with autism spectrum disorders. Table 2.2 identifies the number of school personnel who participated in the surveys by Superintendent's Region. Since the total number of special education teachers and related services personnel serving children with autism spectrum disorders is unknown, it is impossible to determine what percentage of the population responded to the surveys. Given the number of children with autism spectrum disorders in Virginia (see chapter 3), these numbers appear low.

A total of 177 special education administrators received a survey, of which 37% responded. Administrators received a follow-up postcard reminder to complete their survey and to remind their staff to complete the surveys. VDOE staff also reminded administrators about the importance of the study at their regional directors meetings and at a State Council meeting.

Table 2.2
Number of School Personnel and Treatment Provider Survey Respondents
By Superintendent's Region

Superintendent's Region	Special Education Teachers	Related Services Personnel	Special Education Administrators	Treatment Providers
1	25	66	2	7
2	11	41	7	12
3	9	11	5	1
4	55	84	12	14
5	13	31	11	7
6	8	31	8	3
7	8	15	7	4
8	1	5	4	1
Missing Data*	16	30	10	6
Total	146	314	66	55

*Respondents did not provide information regarding the geographic location in which they work.

Only a small number of treatment providers responded to a request for participation in the study. Approximately 100 surveys were mailed directly to treatment providers who were identified by the Autism Society of America chapters, The Autism Program of Virginia, the Virginia Department of Health, and members of the Advisory Panel. A flyer was inserted into each parent survey along with a request to give the survey information to their child's treatment provider(s). Flyers about the study and survey were also distributed via email to approximately 400 members of the National Academy of Pediatricians. The same flyer was included in the conference packets of 200 pediatricians who attended a statewide conference in early May.

The last two surveys focused on LICC coordinators (who serve children from birth to age two) and MR directors at the CSBs. These individuals were mailed a paper copy of the survey. They also received two email reminders from staff at DMHMRSAS regarding the importance of the surveys and the need for completing them. Response rates for both groups were very good, with 63% of the LICC coordinators and 50% of the MR directors submitting surveys (see Tables 2.3 and 2.4). Descriptions of the LICC regions identified in Table 2.3 are provided in Appendix D. CSB regions are described in Appendix E.

Table 2.3
Number of LICC Coordinator Survey Respondents by LICC Region

LICC Regions	Frequency
Abingdon	4
Northern VA	6
Richmond/Central	6
Roanoke	2
Tidewater	4
Valley	3
Total	25

Table 2.4
Number of MR Director Survey Respondents by CSB Regions

CSB Regions	Frequency
1	5
2	1
3	4
4	5
5	3
Missing Data*	2
Total	20

*Respondents did not provide information regarding the geographic location in which they work.

Focus Groups and Group Interviews

Focus groups were held with staff from The Autism Program of Virginia, the Training and Technical Assistance Centers, and the Virginia Autism Resource Center. Each of these organizations provides technical assistance to individuals and teams of school personnel, parents, and other service providers on issues related to serving children with autism spectrum disorders. Focus groups were used to obtain detailed information about each group's experiences with and perceptions of the level of expertise of parents and professionals, the adequacy of available services, the challenges involved with providing technical assistance, and recommendations for improving services for children.

Two group interviews were also conducted with members of the Advisory Panel. Structured questions were posed to the group to obtain information about each of the study questions, including recommendations for improving services for children.

A written summary of the information gathered from focus groups and the group interviews was shared with each respective group to ensure that the information gathered was accurate and reflected the perspectives of the group. Slight modifications were made to some of the summaries based on feedback from the participants.

Existing Databases

Data specific to the study area questions were obtained from existing databases maintained by VDOE, DMHMRSAS, and VDH. Some stakeholder groups who participated in the surveys were also requested to report data from their databases. These groups included Community Services Boards and Local Interagency Coordinating Councils. Limited information about children with autism spectrum disorders was available from the databases consulted.

Study Area 1: The Characteristics, Number, and Location of Children with Autism Spectrum Disorders in Virginia

OVERVIEW

The Virginia Department of Education (VDOE) is the only agency that is mandated to collect information about the number and location of children with autism spectrum disorders in Virginia. These data are limited to children between the ages of 3 and 22. While information is available about the number and location of children with disabilities between birth and age two, these data do not specifically identify children with autism spectrum disorders. In addition, no agency is required to maintain records on the characteristics (e.g., type of autism spectrum disorder, presence of other disabilities) of children with autism spectrum disorders.

Existing data from VDOE indicate steady growth in the number of children with autism spectrum disorders over the last decade. Most children who are identified with an autism spectrum disorder are elementary school aged and are spending less that 60% of their day in the general education classroom. Numerous limitations exist regarding the data and the conclusions that may be drawn. Overall, there appears to be a need for a comprehensive strategy for tracking the number, location, and characteristics of children with autism spectrum disorders in Virginia.

FINDINGS

Children Birth to Age 2

The Department of Mental Health Mental Retardation and Substance Abuse Services (DMHMRSAS) is responsible, under Part C of the Individuals with Disabilities Education Act (IDEA), for collecting data on the number and location of children with disabilities in Virginia between the ages of birth and two who receive early intervention services. Although data are maintained on the "diagnosed disabling condition" of each child, autism is not specifically listed as a condition. Hence, there are no existing data available to report accurately the number of children statewide between birth and age two who are identified with autism spectrum disorders. No other agency collects information on this population statewide.

In Virginia, 40 Local Interagency Coordinating Councils (LICCs) coordinate early intervention services for children birth to age two with disabilities. Each LICC is responsible for reporting data to DMHMRSAS to meet the requirements of Part C of IDEA. These LICCs are grouped according to six geographic regions of the state (see Appendix D for a list of the LICCs in each region). Members of the HJR 228 Study Group and Advisory Panel indicated that many LICCs maintain additional records on the disabilities of the children they serve. In an effort to obtain a general understanding of the number and location of young children with autism, a survey was mailed to each LICC coordinator. A total of 25 surveys (63%) were returned. Twenty-one of the LICCs indicated that they had provided services to children with a documented medical diagnosis of autism spectrum disorders in the previous five years. Table

3.1 presents an overview of the number of children with autism spectrum disorders served in each LICC region during the year in which the December 1, 2000 Child Count was reported.

Table 3.1
Estimated Number* of Children Birth to Age Two with a Medical Diagnosis of Autism Spectrum Disorders or "Autistic Like" Behaviors
Served Through Virginia's Local Interagency Coordinating Councils (LICCs)

	LICC Region						
Number	Abingdon	Northern Virginia	Richmond/ Central	Roanoke	Tidewater	Valley	Total
Number of Children with a Medical Diagnosis of Autism Spectrum Disorders	2	5	17	4	1	4	33
Number of Children with a Medical Diagnosis of "Autistic Like" Behaviors	0	1	18	1	4	0	24

*These data reflect estimates provided by 25 of the 40 LICC Coordinators. Estimates are based on the number of children served during the year when the December 1, 2000 Child Count was reported.

The vast majority of children with a medical diagnosis of autism spectrum disorders or autistic like behaviors were served by LICCs in the Richmond/Central Region. This may be due to the high number of LICCs (n=6) who responded to the survey rather than any substantial differences among the six regions. These data should be viewed with caution since they do not include responses from 15 of the 40 LICCs. Further, since the respondents were not requested to specify where they obtained the data they reported (e.g., databases, child records, personal recollection), the numbers reported may under or overestimate the true population served by the LICCs that responded to the survey.

Children Ages 3 to 22

The Virginia Department of Education (VDOE) is the sole agency responsible for collecting data on the number and location of children with autism spectrum disorders in Virginia. Information about the statewide characteristics of these children (e.g., type of autism spectrum disorder, presence of other disabilities) is not gathered by any agency in Virginia.

Under the Individuals with Disabilities Education Act (IDEA), VDOE is required to collect data annually on the number of children with disabilities who are a) between the ages of 3 and 22, b) enrolled in school (i.e., preschool, elementary, middle, high), and c) receiving special education services and supports as specified by an Individualized Education Program (IEP). Although IDEA does not require schools to serve children below age three, schools that choose to provide services to this population are required to include these children in the data they report. VDOE collects data on the primary, secondary, and tertiary disability of all children; the geographic location (i.e., school and school division) where children receive their education; and the educational placement of each child.

In Virginia, school divisions are organized into eight superintendent's regions (see Appendix C for a list of the school divisions in each region). Each superintendent's region includes school divisions from the same geographic area. Table 3.2 identifies the number of children ages 3-22 with a primary disability of autism spectrum disorders who were reported annually between 1992 and 2000 within each superintendent's region. These data clearly show that schools are experiencing a steady increase in the number of children they serve with autism spectrum disorders. Since 1992, the total number of children statewide has increased from 635 to 2247.

Children for whom autism is a secondary or tertiary disability are not included in the data presented in this chapter. While children with autism as a primary disability are well represented across all school divisions (see Table 3.2), children with a secondary or tertiary disability of autism are primary clustered in one school division. An analysis of the most recent 2000 data found that 90% (n=349) of these children were served in Fairfax County. The other 10% (n=36) of the children were spread across 19 school divisions. Of the 115 school divisions who reported children with autism spectrum disorders, 83% indicated that all of the children they served had autism as a primary disability. It remains unclear why such diversity exists among school divisions with regards to disability identification.

Table 3.2
Number of Children Ages 3-22 Within Each Superintendent's Region
With a Primary Disability of Autism Spectrum Disorders*

	Superintendent Regions								
Year	1	2	3	4	5	6	7	8	Total
1992	50	263	41	198	27	42	12	2	635
1993	59	276	51	225	32	48	13	4	708
1994	70	300	49	275	46	55	16	5	816
1995	78	346	55	303	61	60	21	6	930
1996	154	418	64	342	74	71	27	9	1159
1997	197	442	77	400	90	89	35	9	1339
1998	189	483	89	512	115	90	44	10	1532
1999	274	549	111	723	146	99	47	19	1968
2000*	398	561	126	780	194	111	49	28	2247

Source: Virginia Department of Education

*Unverified count as of July 2001.

The number of [all] children receiving special education services and supports in Virginia has increased dramatically over the last 10 years. In 1991 a total of 115,823 children received special education services and supports. By the year 2000, that number had increased to 161,930 (note that the 2000 data represent an unverified count as of July 2001).

Although the number of children identified with autism increased substantially during this same time period, autism remains a low-incidence disability. As of 2000, children with autism constituted 1.39% of all children receiving special education services and supports in Virginia. Ten years ago (1991), children with autism represented .47% of the population of children receiving special education.

Most children who are identified with autism spectrum disorders are between the ages of five and 10 (i.e., in elementary school). Table 3.3 provides a breakout of the population according to the approximate age groupings of preschool (ages 3-4), elementary school (ages 5-10), middle school (ages 11-13), high school (ages 14-18), and post-high school (ages 19-22). During the past 10 years the number of children reported within each age group has grown on average 406%. This increase is particularly noticeable beginning in 1998. Overall, the greatest growth in children with autism is in the population of 3-4 year olds. This group has evidenced a 513% increase in population over the last decade.

Table 3.3
Number of Individuals Identified with Autism Spectrum Disorders
by Age Between the Years 1991 and 2000

Age Group	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	Percent Increase Over 10 Years
3-4	15	15	17	16	28	35	33	41	68	77	513%
5-10	327	376	410	449	439	654	774	907	1153	1293	395%
11-13	87	104	112	155	174	222	244	259	349	384	441%
14-18	87	97	122	146	166	188	231	246	304	375	431%
19-22	31	30	37	42	51	53	51	68	79	94	300%
Total	547	622	699	808	918	1152	1333	1521	1953	2,223	406%

Note: A comparison of Tables 3.2 and 3.3 shows that there are slight variations in the total number of children reported annually. Although both tables consistently demonstrate the same trends, the source of the differences in the final counts remains unknown.

The most recent data reported by VDOE to the U.S. Department of Education on the educational placement of children with autism in Virginia (see Table 3.4) illustrate the diverse settings in which children are educated. Most children (85%) are educated in a school with peers who do not have disabilities. Despite their inclusion in the school building, 82% of these children received their education outside the general education classroom for more than 60% of the school day. (These data do not differentiate the number of children who were served in a full-time special education classroom from those who received a portion of their education in the general education classroom.) Of the other educational placements identified, public separate facilities were the most frequently selected placement (11%) outside the regular school setting. In fact, public separate facilities ranked as the second most utilized placement overall for children with autism.

Table 3.4
Educational Placement of Children with Autism Spectrum Disorders
During the 1998-1999 School Year

Educational Placement	Age			Total
	6-11	12-17	18-21	
Outside the regular class less than 21 percent of the time	50	22	1	73
Outside the regular class at least 21 percent of the day but no more than 60 percent of the day.	103	31	5	139
Outside the regular class for more than 60 percent of the day.	630	263	63	956
Public separate facility	93	45	16	154
Private separate facility	7	6	5	17
Public residential facility	0	2	3	5
Private residential facility	2	12	12	26
Homebound/hospital placement	2	1	1	4
Total				1374

Source: U.S. Department of Education, Office of Special Education and Rehabilitative Services, Office of Special Education Programs, November 2000

Limitations of the Available Data

Focus group interviews with members of the HJR 228 Advisory Panel and Study Group suggest that the data presented in this chapter substantially underestimate the number of children in Virginia with autism spectrum disorders. They cite the following limitations to obtaining an accurate picture of the number, location, and characteristics of these children:

- There is no system in place to systematically collect information about the number of children birth to age two with autism spectrum disorders.
- Many pediatricians are reluctant to diagnose young children with an autism spectrum disorder. Diagnosis depends on the skills of the evaluator. Many do not have sufficient expertise to make the diagnosis.
- The child count data from VDOE reflect only the number of children with an educational diagnosis of autism spectrum disorders. Children with a medical

diagnosis of autism who do not receive educational services for their disability are excluded from the count.

- Since schools are not required to assign a disability label until age 9 (i.e., they may classify all children with disabilities under the heading of "developmentally delayed") children with autism spectrum disorders may be reported only under the category of "developmentally delayed."
- Some parents avoid having their child identified with an educational diagnosis of autism if they desire a specific placement for their child that is different than what is normally provided for children with autism.
- Some children with autism are served under the disability labels of other health impaired (OHI) or severe emotional disturbance (SED).

Further complicating these issues are recent changes to the federal and state regulations that now give localities permission to identify students with disabilities without assigning a categorical disability label. Schools will still be required to report the number of children they serve by disability label. If parents and/or schools decide to eliminate labeling, it will become increasingly difficult to obtain an accurate picture of the population of children with autism spectrum disorders (and other disabilities) in Virginia.

Study Area 2: The Availability of Teachers and Other Special Education and Treatment Professionals

OVERVIEW

This chapter focuses on (a) the availability of professionals to diagnose autism spectrum disorders, (b) the availability of qualified school personnel, (c) the availability of qualified non-school personnel (i.e., treatment providers), and (d) professionals' access to other professionals with expertise in autism. Survey data were gathered from parents of children with autism spectrum disorders, special education teachers, related services personnel, special education administrators, treatment providers, Local Interagency Coordinating Council (LICC) coordinators, and mental retardation (MR) directors from Community Services Boards (CSB). Interviews with staff from the Virginia Department of Education were also conducted along with a review of the state regulations on teacher licensure.

Survey respondents indicated that the availability of teachers and other special education and treatment professionals for children with autism spectrum disorders vary widely across Virginia. Although most parents were able to obtain an initial diagnosis of autism spectrum disorders from a professional within their locality, the majority experienced difficulty locating service providers following their child's diagnosis. This challenge in locating qualified personnel was acknowledged by special education administrators, LICC coordinators, and MR directors. Inadequate numbers of professionals exist to serve children with autism spectrum disorders in many areas of Virginia.

Despite difficulties with sustaining sufficient numbers of qualified professionals, most direct service providers (special education teachers, related services personnel, treatment providers) indicated that they have access to other professionals in their school/office who have expertise in the area of autism. In fact, most treatment providers indicated that their locality possessed a number of providers from other disciplines with expertise in autism. Although the number of professionals available to provide services to children with autism spectrum disorders appears limited, those professionals who are employed in this capacity frequently have access to other service providers with similar expertise in their locality.

FINDINGS

The Availability of Professionals to Diagnose Autism Spectrum Disorders

The majority of parent respondents indicated that they were able to locate a professional in their locality to diagnose their child with autism spectrum disorders. Of the parents who participated in the survey, nearly half were able to obtain an initial diagnosis within their city or county while 18% traveled less than an hour from home and 15% traveled out of state. Only 31% of the parents surveyed indicated that the services their child needed following diagnosis were available locally.

Parents identified a wide range of professionals who provided their child's initial diagnosis (see Table 4.1). In many instances, parents reported that two or more professionals were responsible for diagnosing their child, which explains why the percentages in Table 4.1 sum to more than 100%.

Table 4.1
Types of Professionals Who Provided an Initial Diagnosis of Autism Spectrum Disorders (N=847)

Type of Professional	Percent
Developmental Pediatrician	27%
Neurologist	24%
Special Education Eligibility Committee	14%
Clinical Psychologist	14%
School Psychologist	10%
Psychiatrist	10%
Primary Care Physician	7%
Other	8%

The majority of special education administrators indicated that most students with autism spectrum disorders in their school division/program receive their initial diagnosis from a professional outside the school (i.e., a professional not employed by the school/program). Administrators' responses varied widely on whether they believed there were qualified professionals within their school division/program and within the local community to diagnose children with autism spectrum disorders.

The Availability of Qualified School Professionals

Special education administrators reported a wide range of responses regarding the ability of their school division/program to locate qualified professionals to work with children with autism spectrum disorders (see Table 4.2). The majority of administrators (57%) agreed that it is more difficult to find qualified professionals to work with students with autism than students with other types of disabilities. Barriers to finding qualified special education teachers for students with autism spectrum disorders included the existence of a teacher shortage in special education (84%), few teachers being trained to work with this population (80%), and few teachers being interested in working with this population (47%). These administrators also indicated a wide range of responses regarding the turnover rate of special education teachers working with children with autism. It appears that the turnover rate may be high in some schools/programs and low in others.

Table 4.2
Administrators' Ratings of Their Ability to Locate Qualified Professionals to Work With Children With Autism Spectrum Disorders (N=66)

Survey Statement	Disagree to Strongly Disagree	Uncertain	Agree to Strongly Agree
Our school division/program is able to locate qualified professionals to work with children with autism.	38%	32%	30%
It is more difficult to find qualified professionals to work with students with autism than students with other types of disabilities.	17%	26%	57%

In Virginia, individuals who teach special education must have a teaching license with endorsement in a specific area. The endorsement areas include learning disabilities, emotional disturbance, mental retardation, severe disabilities, and early childhood special education. There is no specific endorsement offered in the area of autism (nor in many other disability areas). According to the state regulations (section 20-80-45), the teaching license required by a teacher who serves students with autism spectrum disorders should be one that is appropriate to the students' needs. A teacher may hold a license with endorsement in any of the five areas listed above as long as it meets the needs of the child/children the teacher serves. As such, decisions about endorsement(s) for working with children with autism are determined at the local level.

The Virginia Department of Education is responsible for checking to ensure that individuals who seek licensure meet the qualifications of the particular endorsement they are seeking. They also maintain records regarding the number of conditional licenses that are granted in each endorsement area. Since endorsement is not offered in the area of autism, it is impossible to know the number of special education teachers who are employed state-wide in this capacity, their endorsement(s), and the number who have conditional licenses. There has been debate within Virginia about the need for specific licensure in autism spectrum disorders. This specific need was not supported by the data gathered for this study (see recommendations from stakeholder groups), although strong support is present to suggest the need for better preservice and inservice teacher training.

The Availability of Qualified Non-School Professionals

LICC coordinators, MR directors, and parents were asked about the availability of qualified professionals outside the school setting (i.e., treatment providers). LICC coordinators were specifically questioned about the availability of professionals to serve children from birth to age two with autism spectrum disorders. Only 50% of these coordinators indicated that their LICC was able to locate qualified professionals and 40% remained uncertain. MR Directors were less positive about whether their CSB was able to locate qualified professionals to work with individuals under age 22 with autism spectrum disorders. Twenty percent believed their CSB was able to locate qualified professionals while the majority (60%) disagreed.

When parents were asked if they were able find professionals (such as speech therapists, occupational therapists, or behavior specialists) outside of the school setting to serve their child, responses varied across the scale from strongly agree to strongly disagree. This variation in responses was equally present when parents were asked whether they were able to obtain needed services within their locality (as opposed to traveling out of town). In addition, parents reported that they were less able to locate providers for Medicaid Waivers services than for other non-Medicaid Waiver services. Only 36% of the parents (N=33) with a child who was receiving waiver services indicated that they were able to located qualified providers. Clearly, parents' experiences with locating and obtaining services vary dramatically.

Professionals' Access to Other Professionals with Expertise in Autism

Professionals who provide services for children with autism spectrum disorders do appear to have contact with other professionals who have knowledge/expertise in autism. A fairly large majority (71%) of special education teachers reported that there are other special education teachers who teach children with autism in their school.

Most treatment providers (70%) indicated that there are other professionals in their office/practice who have expertise in autism spectrum disorders. The majority also indicated that qualified treatment providers from other disciplines were available in their locality (see Table 4.3).

Table 4.3
Percentage of Treatment Providers Who Indicated There Are Other Professionals In Their Locality Who Provide Services to Children With Autism (N=55)

Type of Service	Percent
Diagnostic Evaluation	60%
Medication Evaluation	70%
Neurological Evaluation	75%
Psychotherapy/Counseling	59%
Behavior Therapy	52%
Speech Therapy	80%
Occupational Therapy	76%
Physical Therapy	78%

Approximately half of the special education teachers (53%) and related service personnel (48%) surveyed reported that they have access to an autism specialist in their school division. Special education administrators reported a wide range in the number of professionals employed as an "autism specialist" in their school division/program. The number of professionals reported ranged from 0 to 50 with an average of approximately 3. Because autism is not an area of teacher endorsement through the Department of Education and there is no credentialing system in place to define an "autism specialist", it remains unclear what role autism specialists play in each school. In some schools/programs, a classroom teacher may be considered an "autism specialist" because he/she works directly with this population. In other schools/programs a teacher specialist or program supervisor may serve in this capacity by consulting with school personnel in several classrooms. Perceptions about the role of an "autism specialist" may well vary among the stakeholder groups, thus making it difficult to define fully the number and qualifications of the individuals employed as autism specialists in Virginia.

Administrators who do not have an autism specialist in their school division/program provided several reasons for not hiring one (see Table 4.4). The most frequent reasons given were that they use outside consultants when they need more expertise and they do not have enough students to justify hiring an autism specialist.

Table 4.4
Percentage Of Special Education Administrators Indicating Reasons For Not Having An Autism Specialist In Their School Division/Program (N=66)

Reason For Not Having An Autism Specialist	Percent
We do not have funds to hire an Autism Specialist	19.7%
We have professionals on staff with expertise in autism	36.4%
We use outside consultant when we need more expertise	43.9%
We do not have enough students to justify hiring an autism specialist	43.9%

Study Area 3: The Level of Expertise Found in the Various Areas of Virginia

OVERVIEW

Study area three addresses the level of expertise found in the various areas of Virginia. This chapter discusses (1) the expertise of professionals who initially diagnose children with autism spectrum disorders, (2) the perceived knowledge of parents, school personnel, and service providers (i.e., professionals who work outside the school setting) regarding autism, (3) the adequacy of the preservice training received by professionals, (4) the adequacy of the inservice training received by professionals, (5) stakeholders' knowledge about education and medical approaches, (6) perceptions of the expertise available within existing disability organizations, (7) stakeholders' familiarity with community services, and (8) the qualifications of teachers. Survey data were gathered from parents of children with autism spectrum disorders, special education teachers, related services personnel, special education administrators, treatment providers, Local Interagency Coordinating Council (LICC) coordinators, and Community Services Board (CSB) mental retardation (MR) directors. In addition, focus groups were conducted with staff from three organizations that provide statewide technical assistance in the area of autism to families, school personnel, and other service providers (i.e., The Autism Program of Virginia, Training and Technical Assistance Centers, Virginia Autism Resource Center).

The findings from Study Area 3 suggest that the level of expertise of professionals working with children with autism spectrum disorders is questionable. Substantial numbers of professionals (somewhat less than 50% across stakeholder groups) reported that they questioned their training and qualifications to work with children with autism spectrum disorders, as well as their knowledge about educational and medical approaches for working with this population. On the whole, a majority of respondents within each stakeholder group reported that they had adequate training in their specific area of endorsement/expertise, but had less confidence in their training specifically for teaching/serving children with autism spectrum disorders. Based on the self-reports of the stakeholder groups it appears that professionals have adequate general training, but that they lack specific information and/or strategies for working with children with autism spectrum disorders. Few professionals indicated that they received adequate preparation to teach children with autism during their preservice training program, and many indicated limited satisfaction with both their access to inservice training and the usefulness of the training they received.

FINDINGS

Expertise Of Professionals Providing Initial Diagnosis

The average age at which parents reported their child was diagnosed with an autism spectrum disorder was four years. The majority of all children (70%) received a diagnosis prior to age 6. Parents indicated that their child had seen an average of 3.65 professionals before obtaining a diagnosis of autism and that on average it took better than two and one half years to obtain the diagnosis. Table 5.1 shows the initial diagnoses that parents indicated were given to their children. These diagnoses reflect the DSM-IV definitions of pervasive developmental disorders (also known as autism spectrum disorders). Many parents selected more than one category.

Table 5.1
Type of Autism Spectrum Disorder With Which Parents Indicated
Their Child Was Initially Diagnosed (N=839)

Initial Diagnosis	Percent
Autism	58%
Asperger's Syndrome	14%
Childhood Disintegration Disorder	.2%
Pervasive Developmental Disorder (PDD)	27%
Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)	14%
Rett's Disorder/Rett's Syndrome	.4%

Parents were asked to describe the usefulness of the information they received about available medical treatments, educational approaches, and community resources from the professional who first diagnosed their child with autism spectrum disorders. The data presented in Table 5.2 show that there is great variability in the usefulness of the information parents received. It is noteworthy that more than 30% reported they did not receive any information about medical treatments or community resources when their child was initially diagnosed. When combined with the percent of parents who felt the information they received was not helpful, it becomes apparent that fewer than half of the respondents found the information they received on medical treatments and community resources to be useful. Information about educational approaches appears to be more widely available.

Fifty percent of the treatment providers reported that they diagnosed children with autism spectrum disorders within the 12 months prior to completing the survey. (Since the treatment provider survey was designed for various non-school professionals who serve children with autism spectrum disorders, it was expected that only a fraction of those completing the surveys would perform services that included initial diagnosis.) Each treatment provider diagnosed an average of nine children during the 12 months prior to completing the survey, with an average of 3.5 of these children being under the age of 3.

Treatment providers also responded to questions about their qualifications to diagnose children with autism. A majority (64%) reported that they had received adequate training to diagnose children with autism spectrum disorders. A smaller percentage (37%) reported that they felt confident diagnosing children under the age of 3. Treatment providers (77%) reported much greater confidence in diagnosing autism spectrum disorders in children over the age of 3. A fairly small percentage (40%) believe that the guidelines for diagnosing children are clear, and a sizable majority (80%) reported that when they are uncertain about diagnosing a child with an autism spectrum disorder, they refer the child to another specialist.

Table 5.2
Usefulness of the Information Parents Received About Medical Treatments, Educational Approaches, and Community Resources from the Professional Who First Diagnosed Their Child with Autism Spectrum Disorders

	Medical Treatments (N=582)	Educational Approaches (N=777)	Community Resources (N=570)
Very Useful	15.2%	24.3%	13.3%
Useful	14.8%	20.8%	14.0%
Somewhat Useful	16.6%	21.8%	19.2%
Not Useful	19.8%	16.2%	22.2%
Did not receive Information	31.3%	16.9%	31.1%

Overall it appears that the availability of qualified treatment providers to diagnose children with autism spectrum disorders is questionable. Data obtained from focus groups with staff from three state-wide technical assistance organizations further support this conclusion. Within one focus group, everyone agreed that finding qualified treatment professionals to diagnosis young children with autism spectrum disorders was difficult. Their experiences suggest that parents are traveling outside the state (e.g., North Carolina, Tennessee, Maryland, DC) to obtain an initial diagnosis for their child because diagnoses are not happening early enough in Virginia. Pediatricians are telling parents "just wait and see". These pediatricians end up being the "gatekeepers". According to the focus group participants, almost no pediatricians refer parents to Part C early intervention services. Participants also reported that doctors are reluctant to put a label on a child until he/she reaches school age. Without the label, the child gets put into a classroom that is not intense enough to meet his or her needs.

Perceived Knowledge of Parents, School Personnel, Treatment Professionals, and Community Service Providers Regarding Autism

Parents were asked to rate how knowledgeable about autism spectrum disorders they believed the professionals were who worked with their child. Separate ratings were obtained for professionals who work in the school setting (i.e., school personnel) and those who work outside the school setting (i.e., treatment providers). Table 5.3 describes the ratings obtained from parents.

Among school personnel, autism specialists, behavior therapists, and special education teachers were viewed as the most knowledgeable individuals regarding autism spectrum disorders. In contrast, general education teachers, paraprofessionals, and guidance counselors were perceived as the least knowledgeable. Parents' perceptions of school personnel largely broke out by the specificity of the role of professional. In general, professionals with more specialized expertise in educating children with disabilities were thought to be the most knowledgeable about autism spectrum disorders. Given the number of children who participate in general education classrooms, it is disconcerting that few parents believe general educators and paraprofessionals are knowledgeable about autism.

Table 5.3

Percentage of Parents Who Found the School Personnel and Treatment Providers That Work with Their Child to be Knowledgeable About Autism Spectrum Disorders

	School Personnel		Treatment Providers	
	N	%	N	%
Autism Specialist	394	77%	*	*
Behavior Specialist	226	71%	172	85%
Clinical Psychologist/Counselor	*	*	223	72%
Community Services Board (CSB)	*	*	139	43%
Developmental Pediatrician	*	*	409	74%
Early Intervention Specialist	*	*	117	56%
General Education Teacher	617	21%	*	*
Guidance Counselor	360	29%	*	*
Job Coach/Transition Coordinator	121	62%	*	*
Neurologist	*	*	400	68%
Occupational Therapist	615	61%	224	73%
Paraprofessional/Teachers Assistant	736	43%	*	*
Physical Therapist	258	59%	84	61%
Primary Care Physician/ Family Doctor	*	*	759	32%
Psychologist	393	59%	258	70%
Rehabilitative Services Counselor	*	*	33	57%
Residential Program Staff	*	*	30	63%
Respite Care Provider	*	*	128	43%
Special Education Teacher	808	68%	*	*
Speech and Language Therapist	769	60%	320	75%

*Does not apply to this group

Ratings of treatment providers who serve children outside the school setting are overall higher than those obtained for school personnel. Parents appear more satisfied with the knowledge level of these professionals. Where a particular type of professional (e.g., behavior therapist, occupational therapist) could provide services in both school and non-school settings, parents consistently rated the professionals who worked with their child outside the school setting as being somewhat more knowledgeable. Despite the overall high ratings for treatment providers, few primary care physicians, respite care providers, and staff at the Community Services Boards were viewed as possessing knowledge about autism.

Differences in the ratings between school and non-school professionals may be due to a wide variety of issues: parents may have higher expectations when they pay for services; the intensity and/or frequency of some services may be greater in non-school settings; parents may have more direct contact with non-school professionals; or they may simply receive better services from some non-school professionals. Because additional data were not collected to answer this question, it is impossible to explain the cause of these differences. It is interesting to note that statewide, 67% of the parents surveyed agreed that they themselves were knowledgeable about approaches for treating autism.

Narrow majorities of the professionals working with children with autism spectrum disorders reported that they felt qualified to work with this population (see Table 5.4). Somewhat less than half of each of these groups were either unsure of their qualifications or reported that they were not qualified. Of the treatment providers surveyed, 29% considered themselves experts in the area of autism spectrum disorders. (Special education teachers and related services personnel were not asked if they considered themselves experts.)

Table 5.4
Percentage of Professionals Who Believe They Are Qualified to
Work With Children With Autism with Autism Spectrum Disorders

Type of Professional	Percent Agreement
Special Education Teachers (N=146)	52%
Related Service Providers (N=314)	63%
Treatment Providers (N=55)	62%

Perceptions of Professionals Regarding Their Knowledge of Educational Approaches, Medical Approaches, and Community Services

In general, small numbers from each stakeholder group rated themselves/their staff as knowledgeable about medical approaches for treating autism and somewhat more knowledgeable about educational approaches (see Table 5.5). Taken together, these data are less than encouraging, showing that nearly half of the stakeholders were either uncertain about their knowledge about educational approaches or disagreed that they were knowledgeable. The lower rating for knowledge about medical approaches is understandable given that this type of knowledge is not used on a daily basis by most of the groups surveyed.

Data regarding professionals' familiarity with community services suggest an uncertainty among these groups about the community services available for children with autism. Many professionals (e.g., 40% of treatment providers and special education teachers) neither agreed nor disagreed that they were knowledgeable about community services. LICC coordinators and MR directors noted the highest ratings, although their answers were varied as well.

Table 5.5
Percentage of Stakeholders Who Agree They/Their Staff Are Knowledge About Educational and Medical Approaches for Children with Autism Spectrum Disorders

Stakeholder Group	Percent Knowledgeable About Educational Approaches	Percent Knowledgeable About Medical Approaches
Special Education Teachers (N=146)	60%	26%
Related Services Personnel (N=314)	57%	28%
Treatment Providers (N=55)	52%	49%
MR Directors (N=20)	20%	10%
LICC Coordinators (N=25)	50%	28%

Adequacy of Preservice Training Received by Professionals

Special education teachers, related service personnel, and treatment providers were very similar in their self-reports of the adequacy of their preservice training. In general, stakeholders indicated that they received adequate training to teach and/or work with children in their particular area of endorsement or specialty area. Much smaller percentages reported receiving adequate training to specifically teach/work with children with autism spectrum disorders (see Table 5.6). Similarly, the majority of these stakeholder groups indicated that they had received information about autism in their preservice training; however, a much smaller percentage indicated that specific strategies for teaching/working with children with autism were covered. Lastly, 50% of treatment providers and less than half of special education teachers and related services personnel reported that they had field experiences that involved working with children with autism spectrum disorders.

Data obtained from focus groups with staff from three state-wide technical assistance organizations confirm that many of the professionals who request technical assistance have not been properly trained to work with children with autism spectrum disorders. One participant noted "I feel like we're sometimes doing that [training teachers] one teacher at a time." Another participant pointed out that "In most cases [when providing technical assistance] we're dealing with Autism 101" [referring to the low level of expertise required to meet the needs of individuals who do not have any training in ASD]. She equated the organization's services to providing a "Band-Aid Approach" because they are only meeting the immediate needs of the individuals who request services.

Table 5.6
Percent of Stakeholders Who Indicated They Had Adequate Preservice Training
To Work with Children with Autism Spectrum Disorders

	Special Education Teachers (N=146)	Related Services Personnel (N=314)	Treatment Providers (N=55)
Received adequate training during college/professional training to teach/work with children in endorsement/specialty area	64%	73%	62%
Received adequate training during college/professional training to teach/work with children with autism spectrum disorders	13%	20%	36%
Received information about autism in college/professional training	62%	63%	70%
Specific strategies for teaching/working with children with autism were covered in college/professional training	24%	28%	40%
Participated in field experiences during college/professional training that involved working with children with autism.	34%	38%	50%

Adequacy of Inservice Training Received by Professionals

In addition to questions about preservice training, special education teachers and related services personnel were asked about the adequacy of the inservice training they received on autism. In general, both groups reported that conferences and workshops improved their skills in working with children with autism more so than school inservice training (see Table 5.7), although neither form of training appears to have been overwhelmingly effective for either group.

Table 5.7
Percentage of Special Education Teachers and Related Services Personnel
Who Indicated that the School Inservices and Conferences/Workshops They Attended in the
Last 12 Months Improved Their Skills in Working With Children With Autism

Type of Training	Special Education Teachers (N=146)	Related Service Providers (N=314)
School Inservices	30%	30%
Conferences and Workshops	46%	55%

When asked what barriers they faced in trying to obtain additional training in autism, both special educators and related services providers reported that limited school funding was the primary barrier. Teachers appeared to perceive greater barriers to obtaining training than did related services personnel (see Table 5.8).

Table 5.8
Percentage of Special Education Teachers and Related Services Personnel Indicating Barriers to Obtaining Additional Training in Autism

Type of Barrier	Special Education Teachers (N=146)	Related Service Providers (N=314)
Limited school funding to attend workshops/conferences	48%	56%
Unable to secure release time from professional responsibilities	32%	26%
Hard to find substitutes to cover my classes	40%	28%
The location of the trainings are too far away	45%	20%
The training topics don't meet my needs	23%	23%
The training occurs outside normal work hours	30%	19%
I don't face any barriers to obtaining training	8%	12%

Lastly, special education teachers, related services personnel, and treatment providers reported the recency of their attendance at a conference or seminar that addressed the needs of children with autism (see Table 5.9). These data show a great deal of consistency among the groups, with a slight majority having attended a conference or similar event in the previous 12 months. Notable, however, are the 20-30% of professionals who have not participated in a conference or seminar in over 2 years. Since data were obtained on conference/seminar attendance only, it is possible that these professionals may be participating in professional development through alternative methods (e.g., university course, reading journal articles, consultation from a technical assistance provider).

Table 5.9
Length of Time Since Professionals Indicated They Last Attended a Conference or Seminar That Addressed the Needs of Children with Autism Spectrum Disorders

Date of Last Conference or Seminar Attended	Special Education Teachers (N=146)	Related Services Personnel (N=314)	Treatment Providers (N=55)
Within the last 12 months	59%	56%	51%
12-24 months ago	18%	21%	18%
More than 24 months ago	12%	14%	18%
I have never attended a conference or seminar that addressed	10%	8%	13%

Expertise Within Existing Disability Organizations

Parents were asked to rate the helpfulness of the services they or their child received from several disability organizations. Table 5.10 shows the percentage of parents who reported accessing each organization and the percent who found the services helpful. Perhaps the most important observation made from these data is that the majority of parents have not accessed services from these groups. Anecdotal comments from the surveys suggest that there is a lack of knowledge about the existence of some organizations. This might help to explain the low percentage of parents who access their services. Although perceptions of each organization's helpfulness varied, ratings of services obtained from parent organizations (i.e., the first four organizations listed) were substantially higher than most other disability organizations. These four organizations offer information, training, and support for parents whereas the other three organizations offer services and funding for children with disabilities.

Table 5.10
Percentage of Parents Who Have Received Services From
Existing Disability Organizations and Found the Services Helpful (N=847)

Disability Organization	% Who Have Received Services	% Who Found Services Helpful
Autism Society of America – Virginia Chapter	53%	70%
Autism Support Group/Parent Advocacy Group	37%	75%
Parent Education Advocacy and Training Center (PEATC)	25%	62%
Parent Resource Center	48%	61%
Community Services Board (CSB)	24%	58%
Department of Rehabilitative Services (DRS)	8%	34%
Social Security Administration	28%	43%

Parents, special education teachers, related services personnel, and special education administrators were asked to rate the helpfulness of services received from Virginia's three state-wide technical assistance providers (see Table 5.11). These providers include The Autism Program of Virginia (TAP-VA), the Training and Technical Assistance Centers (T/TACs), and the Virginia Autism Resource Center (VARC). Overall, it appears that the services available from these organizations are underutilized. Teachers and related services personnel in particular underused the services of VARC and TAP. Parents consistently underutilized all technical assistance services. In fact, following the surveys, many parents telephoned the study director to obtain more information about these and other services they saw listed in the survey.

Given the diverse needs of the individuals who request technical assistance, it is difficult to draw conclusions about the helpfulness of the services provided by each technical assistance provider. With the exception of special education administrators, stakeholders who obtained services from a technical assistance provider were generally satisfied with the help they obtained. Some of the differences in administrator perceptions could be due to the level of contact they have with each of the providers. For example, special education administrators have at least monthly contact with T/TAC personnel (through regional meetings), but they do not have this level of contact with the other providers. In addition, the T/TACs tend to maintain sustained contact with administrators through long-term agreements to work with the schools to create systems change. TAP and VARC respond primarily to student specific requests for assistance and are not generally involved in systems change efforts.

Table 5.11
Percentage of Stakeholders Who Have Received Services From State-Wide Technical Assistance Providers and Found the Services Helpful

	The Autism Program of Virginia (TAP-VA)		Training and Technical Assistance Center (T/TAC)		Virginia Autism Resource Center (VARC)	
	% Who Have Received Services	% Who Found Services Helpful	% Who Have Received Services	% Who Found Services Helpful	% Who Have Received Services	% Who Found Services Helpful
Special Education Teachers	19%	63%	45%	68%	18%	59%
Related Services Personnel	20%	73%	54%	80%	27%	66%
Special Education Administrators	57%	14%	82%	85%	76%	20%
Parents	26%	70%	23%	67%	13%	47%

Study Area 4: The Adequacy of the Available Services for Children with Autism Spectrum Disorders

OVERVIEW

Study area four addresses the adequacy of the available services for children with autism. This chapter discusses (1) the waiting period prior receiving initial services, (2) additional services needed, (3) access to education and treatment approaches, (4) the adequacy of the types and amount of services children with autism spectrum disorders receive, (5) the ability of providers to meet the needs of children, (6) the adequacy of general and special education classroom staffing, (7) Medicaid Waiver services, (8) insurance coverage, and (9) the cost of services. Survey data were gathered from parents of children with autism, special education teachers, related services personnel, treatment providers, special education administrators, Local Interagency Coordinating Council (LICC) coordinators, and Community Services Board (CSB) mental retardation (MR) directors. In addition, a focus group was conducted with the Advisory Panel to determine their perceptions about the adequacy of services in Virginia.

Taken together, the data collected among the various stakeholder groups suggest that there is a good deal of variability in the adequacy of available services for children with autism. This variability can be seen in the way the majority of the descriptive statistics show a clustering of responses in the center of the various survey item scales with fewer responses on the positive and negative ends (see Study Area 4 tables for examples). Survey data of this type tell us that there is little agreement among the various stakeholder groups, indicating a wide range of opinions and perceptions.

While these data do not suggest a clearly positive or negative atmosphere in the state regarding the adequacy of the available services, substantial portions of the various stakeholder groups reported a lack of adequacy of available services. For example, just over half the special education administrators surveyed reported that parents of children with autism spectrum disorders have requested services that their school division/program was unable or chose not to provide. Only little better than half of special education teachers, related service personnel, and special education administrators agreed that children with autism spectrum disorders receive the types and amount of services they need at school. Lastly, a large majority of special education teachers, special education administrators, and related services personnel indicated that general education classrooms are not staffed appropriately to meet the needs of children with autism spectrum disorders. Parents' responses to all of these questions varied tremendously. Somewhat higher ratings were given regarding the staffing of special education classrooms. In summary, these data show wide variability in responses, possibly indicating a variation among schools, school divisions, and geographic regions of the state. Other variability may be due to age of the child and the disability level (i.e., mild or severe).

FINDINGS

Waiting Period Prior to Receiving Initial Services

The majority of parents (66%) reported that once their child was diagnosed with an autism spectrum disorder, it took between one month and greater than three months before their child began receiving services to address his/her disability. Of these parents, a substantial number (33%) reported waiting over three months before their child received services.

Additional Services Needed

Parents, special education teachers, and related services personnel reported that their children/students with autism spectrum disorders need additional services that they are not currently receiving. Across groups, behavior therapy, sensory integration, counseling, and respite services were among those that were perceived as most needed (see Table 6.1). One quarter of the parents also indicated a need for speech and language therapy.

Table 6.1
Type of Additional Services Needed and Percentage of Stakeholders Indicating a Need for These Services

Services Needed	Special Education Teachers (N=146)	Related Services Personnel (N=314)	Parents (N=847)
Behavior Therapy	46%	41%	38%
Sensory Integration	44%	33%	31%
Counseling	27%	26%	14%
Respite Services	26%	32%	25%
In-Home Care	16%	18%	13%
Vocational Training/Job Placement	15%	13%	8%
Tutoring	14%	12%	20%
Medical Management	12%	17%	10%
Speech and Language Therapy	10%	7%	25%
Occupational Therapy	8%	9%	21%
Physical Therapy	4%	6%	9%

Parents cited several reasons why their child was not receiving the services they perceived were needed. The most frequent explanations provided were that they were not able to afford the needed services (33%), their insurance refused to cover the cost of the services (28%), trained professionals were not available to provide the services (17%), their school refused to provide the services (17%), services were not available in their area of the state (11%), their child was on a waiting list for the service (10%), and their child did not qualify for the service (7%).

Parents, special education teachers, and related services personnel were also asked what additional services their children/students would need in the next three to five years. Stakeholder perceptions were surprisingly consistent across the three groups (see Table 6.2). Speech and language therapy, behavior therapy, occupational therapy, and sensory integration were the services these stakeholders believed would be most needed in the near future.

Table 6.2
Type of Services Needed in the Next 3-5 Years and
Percentage of Stakeholders Indicating a Need for These Services

Services Needed	Special Education Teachers (N=146)	Related Services Personnel (N=314)	Parents (N=847)
Speech and Language Therapy	54%	62%	68%
Behavior Therapy	59%	62%	59%
Occupational Therapy	42%	57%	53%
Vocational Training/Job Placement	47%	56%	31%
Sensory Integration	53%	53%	39%
Counseling	45%	47%	35%
Medical Management	24%	44%	27%
Respite Services	34%	44%	31%
Tutoring	30%	25%	40%
Physical Therapy	14%	23%	15%
In-Home Care	20%	23%	15%

Access To Education and Treatment Approaches

The large majority of special education teachers, related services personnel, special education administrators, and treatment providers indicated that there is not a specific approach to serving children with autism spectrum disorders that is advocated in their school/program, school division, or medical practice. In addition, a majority of special education teachers (61%), parents (58%), and related service personnel (76%) reported that parents do have an option to choose a different approach than what might be offered to their child. Only 36% of the treatment providers reported that parents who contract with them for services have a choice in the approach used with their child.

Statewide, 35% of the parents reported that they had on at least one occasion requested an approach that was denied by the professionals serving their child. These parents offered several explanations for why their request had been denied. These included: trained professionals were not available to implement the approach (46%), the treatment team did not support using the approach (40%), the approach cost too much money (40%), and the treatment team was not knowledgeable about the approach (35%).

A large percentage of special education administrators (54%) indicated that in the past five years, parents of children with autism spectrum disorders had requested services that their school division/program was unable to provide or chose not to provide. The primary reasons given for not providing the services requested were that the Individualized Education Program (IEP) team did not agree that the service was needed or appropriate (51%) and that there was an equally effective service already available through the school (29%).

Most MR directors (80%) indicated that in the last five years, parents of individuals under age 22 with autism spectrum disorders requested services that they were unable to provide or chose not to provide. Slightly fewer than half (43%) of the LICC coordinators voiced the same experiences with parents of children from birth to age two. For both of these groups, the lack of qualified professionals available to provide the desired services was the most frequently cited reason for not providing the requested service.

Adequacy of the Types and Amount of Services Children with Autism Spectrum Disorders Receive

Each of the seven stakeholder groups surveyed were asked to rate the adequacy of both the types and amount of services available for children with autism spectrum disorders. A narrow majority of special education teachers, related services personnel, special education administrators, and LICC coordinators agreed that children with autism spectrum disorders receive the types of services they need (see Table 6.3). Parents' responses to this same question varied across the scale from strongly agree to strongly disagree. MR directors clearly felt the least comfortable with the types of services their CSB offers children with autism spectrum disorders. This might be expected given that CSBs are not specifically funded to serve children with autism, unless the child has also been identified with mental retardation or mental health disabilities. In some cases survey respondents indicated that when they responded to this question they were not sure whether the question addressed school services, community services, or both. For these individuals, it appears that the types of services available in one setting (i.e., school or community) may be adequate while the services available in the other setting may be inadequate.

Satisfaction regarding the amount of services available for children with autism spectrum disorders was slightly lower across most stakeholder groups (see Table 6.4). Special education administrators were the only group where a majority of the respondents believed that these children receive the amount of services they need. Although there was variability within each group's responses, all other stakeholder groups indicated substantial concerns about the amount of services children receive. MR directors and parents voiced the greatest concerns about services.

Table 6.3
Percentage of Stakeholders Indicating That Children with Autism Spectrum Disorders Receive the Types of Services They Need

	Agree to Strongly Agree	Uncertain	Disagree to Strongly Disagree
Parents (N=847)	43%	27%	29%
Special Education Teachers (N=146)	50%	25%	25%
Related Services Personnel (N=314)	51%	26%	23%
Special Education Administrators (N=66)	59%	28%	13%
LICC Coordinators (N=21)	62%	33%	5%
MR Directors (N=20)	25%	20%	55%

Table 6.4
Percentage of Stakeholders Indicating That Children with Autism Spectrum Disorders Receive the Amount of Services They Need

	Agree to Strongly Agree	Uncertain	Disagree to Strongly Disagree
Parents (N=847)	30%	26%	42%
Special Education Teachers (N=146)	43%	22%	34%
Related Services Personnel (N=314)	49%	24%	27%
Special Education Administrators (N=66)	57%	27%	16%
LICC Coordinators (N=21)	38%	38%	24%
MR Directors (N=20)	25%	10%	65%

Ability of Providers to Meet the Needs of Children

The majority (58%) of special education administrators believed they were able to meet the educational needs of students with autism. Administrators also reported the relative expense of educating students with autism compared to students with other types of disabilities. The majority (60%) agreed that it was more expensive, while 20% were uncertain and the remaining 20% disagreed. Only 28% of the special education administrators felt they had adequate funds to meet the needs of children with autism spectrum disorders. These differences in reports of relative cost, adequacy of funds, and ability to meet the needs of students may be due in part, to the variability in services available in different schools, school divisions, and programs.

Survey data from the LICC coordinators show a range of responses regarding their ability to meet the needs of children with autism, with 28% agreeing, 36% uncertain, and the remaining disagreeing. Survey data from MR directors on the other hand are strongly skewed to the negative end of the scale, with 65% disagreeing that they are able to meet the needs of individuals under age 22 with autism spectrum disorders.

Adequacy of General and Special Education Classroom Staffing

A large majority of special education teachers (63%), related services personnel (76%), and special education administrators (72%) believe that the general education classrooms in their building are not staffed appropriately to meet the needs of children with autism spectrum disorders. Parents' responses to this question varied widely with an almost equal percentage reporting satisfaction, dissatisfaction, and uncertainty about the staffing in their child's general education classroom. These data raise questions about whether children with autism spectrum disorders are receiving the support they need to be successful in the general education setting.

Somewhat higher ratings were given regarding the staffing of special education classrooms. Thirty-one percent of special education teachers, 54% of special education administrators, and 60% of parents agreed that special education classrooms were staffed appropriately to meet the needs of children with autism spectrum disorders. Responses from related services personnel varied. Given the low ratings of special education teachers and the inconsistent responses of related services personnel, it appears that those who work with this population on a daily basis in the special education classroom are the most concerned about the adequacy of staff resources. This is an interesting finding considering that the majority of special education administrators (61%) indicated that the caseloads of special education teachers were lower than the maximum allowed in the state regulations and 38% reported that caseloads were at the maximum allowed.

Medicaid Waiver Services

Virginia operates two Medicaid Waiver programs: the Mental Retardation (MR) waiver and the Developmental Disabilities (DD) waiver. These programs are designed to provide services and supports that enable individuals with significant disabilities to remain in the community and avoid institutional placement. Only a very small percentage of children with autism spectrum disorders are receiving Medicaid Waiver services. Nine percent of the parents who were surveyed reported having applied for the MR Waiver. Of this group, 17% indicated that their child was receiving waiver services. Slightly fewer parents (12%) reported having applied for the DD Waiver and only 5% of these parents had children who were receiving services. An additional 35% said that their child qualified for one of the waivers (on average five months ago) but were not receiving services and 30% were waiting to have their child evaluated for services.

Very few children with autism spectrum disorders are receiving Medicaid Waiver services. Parents of children who are receiving services have had mixed experiences with the

Medicaid Waiver program (see Table 6.5). These data continue to show the great variability that exists in the perceived adequacy of services in Virginia.

Table 6.5
Parents' Perceptions of the Medicaid Waiver Program (N=847)

	Agree to Strongly Agree	Uncertain	Disagree to Strongly Disagree
It took a long time for my child's Medicaid Waiver application to be approved.	46%	17%	37%
I am able to locate providers for Medicaid Waiver services.	36%	36%	27%
Medicaid Waiver services have improved my child's quality of life.	61%	24%	15%
My child could not live at home without Medicaid Waiver services.	45%	24%	30%

Survey data collected from MR directors (at the Community Services Boards) strongly indicate that there are not adequate funds available to support individuals who need Medicaid Waiver services. All MR directors responded either that they were uncertain about the adequacy of funds or disagreed that there were adequate funds. In addition, MR directors reported that there is not good coordination between the Community Services Boards and the Department of Medical Assistance Services regarding Medicaid Waiver Services.

Highlighting the very limited number of individuals who access waiver services, MR directors were asked to provide information about the numbers of children who qualified for MR waiver services. Of the 20 (50%) MR directors who completed the survey, it was reported that only 8 individuals under age 22 with a documented medical diagnosis of autism spectrum disorders received services through the MR waiver program in 2000. In addition, MR directors reported that there were 6 individuals under age 22 who qualified for services through the MR Waiver program but did not receive services in 2000. It is important to note that most Community Services Boards do not keep records on the number of children they serve with autism spectrum disorders (or other disabilities outside of mental retardation and mental health). As a result, these numbers may under or over estimate the number of children who actually benefited from the program.

Insurance Coverage

When asked about insurance coverage for their child with autism spectrum disorders, only 14.4% of the parents indicated that their insurance policy fully covers their child (see Table 6.6). In most instances, they reported that their policy covers some services related to autism (44.3%) or does not cover any services related to autism (32.7%). Some parents (4.2%) were completely denied coverage for their child.

Table 6.6
Type of Insurance Coverage Parents Have For
Their Child with Autism Spectrum Disorders (N=786)

Type of Insurance Coverage	Percent
Policy fully covers child	14.4%
Policy covers child and some services related to autism	44.3%
Policy covers child but does not cover services related to autism	32.7%
Policy does not cover child	4.2%
Family does not have health insurance	4.5%

Of the parents surveyed, 304 (39%) indicated that they had been denied coverage (by their insurance company) for a service their child received. The rationales parents were given by their insurance company for not covering the service were that the treatment/therapies/tests were not medically necessary (30%), autism and developmental disorders are excluded diagnoses from the insurance policy (19%), the requested treatment/therapy/test is not a covered service (19%), and autism is not a medical condition (17%).

Cost of Services

Most parents (72%) reported that during the last three years they incurred out of pocket expenses for services related to their child's disability (see Table 6.7). Medical treatments and speech therapy services were the most frequently purchased services. Parents who chose to pay for services frequently purchased more than one type of service for their child. While the costs of services varied widely, behavior therapy and tutoring were on average the most expensive services parents purchased.

Several parents indicated that they incurred one-time costs for certain services. These services are not reflected in Table 4.5. One-time expenditures were for items and services such as augmentative communication devices, summer camp, evaluations, learning supplies, transportation, hearing aides, adaptive sports programs, hospitalizations, and dolphin swims. Some parents noted a loss of income due to taking time off from work or discontinuing work in order to care for a child. Decreases in salary prevented them from purchasing some of the services they felt would be beneficial for their child. It should be noted that some parents indicated that they did not purchase any services for their child, but wanted the additional services and were simply unable to afford them.

Table 6.7
Percent of Parents Who Paid for Services Out of Pocket During the Last 3 Years and Average Monthly Cost of the Services (N=847)

Type of Service	Percent of Parents Who Paid For This Service	Average Monthly Cost
Medical Treatment	34%	$179
Speech Therapy	27%	$273
Occupational Therapy	16%	$244
Behavior Therapy	16%	$726
Counseling	13%	$141
Respite Services	12%	$195
Tutoring	7%	$409
Sensory Integration	5%	$251
Physical Therapy	2%	$255

Advisory Panel Members' Perceptions of the Adequacy of Services

Members of the HJR 228 Advisory Panel participated in a focus group to discuss the services available for children with autism spectrum disorders. There was overwhelming consensus within the group that Virginia's services are not adequate. Members of the Advisory Panel offered the following comments about Virginia's services.

- Services are inadequate regardless of where a child falls on the "spectrum."

- If family members are strong advocates they will get good services. Services do not automatically appear unless a family persists in trying to obtain them.

- Some schools have great services for children with autism and others do not. As a result, some parents must have their child change schools to get the services they need.

- Special education directors are unable to find qualified staff. Once they locate and train staff, the staff leave.

- Not all educational approaches are equally available across the state. Schools need more information about approaches for educating children with autism spectrum disorders and the community services that are available.

- There is little coordination among physicians across the state regarding treatment approaches.

- Community Services Boards are serving an increasing number of children with autism spectrum disorders. In order to qualify for services, the child must have a dual diagnosis of mental retardation and autism or mental health disabilities and autism. CSB services focus on the child's needs that result from mental retardation or mental health and do not necessarily consider needs that are specific to autism.

- Budgets and professional expertise influence the availability and adequacy of services.
- There is a great need for helping parents to understand about the services that are available for their child.
- Virginia's service delivery system (i.e., excluding the educational system) focuses only on mental retardation and mental health disabilities. It does not address the needs of individuals with developmental disabilities. Services are based on the individual's disability label. Some children with autism spectrum disorders receive services through this system because they are the best they can get; not because they are necessarily the "right" services.

Study Area 5: The Efficacy of the Various Treatment Approaches

OVERVIEW

Study Area 5 addresses the efficacy of various approaches to educating and treating autism. Twenty approaches were reviewed. These approaches were identified and selected by the HJR 228 Advisory Panel based on their expertise and knowledge of approaches for working with children with autism spectrum disorders. The efficacy of the approaches were studied by a) conducting a preliminary, but not exhaustive, review of the research literature on each approach, and b) surveying parents and professionals regarding their perceptions of the effectiveness of the approaches. Within the literature review, emphasis was placed on trying to provide an objective description of the range of findings on each approach, noting where the literature was absent or limited (including the presence or absence of empirically-based studies), and identifying methodological problems cited or observed. To maximize the integrity of the survey data, parent respondents were asked only to rate the effectiveness of those approaches that had been used with their child, and professionals were asked only to rate the effectiveness of approaches that had been used with the children they serve.

Preliminary findings from the literature review suggest that few approaches offer substantial empirical evidence to support their effectiveness. Of the approaches reviewed, applied behavior analysis provided the most substantial number of empirically-based studies. The benefits of early intervention, positive behavior supports, and augmentative communication were also well documented. For two of the approaches, chelation therapy and SCERTS (Social Communication Emotional Regulation and Transactional Supports), no literature was located to indicate that the approach had been scientifically investigated. Most other approaches were supported by a limited amount of research. In some cases, the approach (e.g., inclusive education) had been extensively researched but information on its specific benefits for children with autism was limited. Controversial approaches identified in the literature include auditory integration training, facilitated communication, and secretin. Given the current debate surrounding the efficacy of practices for educating children with autism, researchers are increasingly supporting the use of multiple educational approaches that are based on the individual needs of the child (Heflin & Simpson, 1998; Smith, 2001). Additional research is clearly needed to extend our understanding of the effectiveness of all approaches for children who fall across a very diverse spectrum of disability.

Surveys conducted with parents, special education teachers, related services personnel, and treatment providers (i.e., non-school professionals) in Virginia provided an array of perceptions regarding the efficacy of the 20 approaches. More respondents reported experience with general approaches (i.e., approaches widely used with children with diverse disabilities) than specific approaches (i.e., approaches primarily advocated for children with autism). All of the 20 approaches were perceived to be effective by at least some of the respondents. Across stakeholder groups, the picture exchange communication system (PECS) and positive behavior supports (PBS) were the two strategies that garnered the highest percentage of respondents across stakeholder groups who believed the approach was effective. Less than half of all respondents in the four groups found auditory integration training, facilitated communication, secretin, special diet, and vitamin therapy to be effective. Since these data rely on perceptions rather than empirical evidence, they provide valid information about the experiences of stakeholders in Virginia but not about the efficacy of the approaches. Data from these surveys support the need for multiple approaches and the selection of approaches based on the individual needs of the child.

INTRODUCTION

In recent years there has been a great deal of discussion regarding the efficacy of the various approaches to educating and treating children with autism. Lack of consensus exists within the field regarding the effectiveness of the available approaches. Based on a review of numerous outcome studies, Prizant and Rubin (1999) came to the following conclusions:

- Research has supported the effectiveness of a range of approaches
- No evidence exists that any one approach is more effective than others
- No one approach is equally effective for all children
- Available research suffers from methodological shortcomings
- Studies have focused solely on child variables and child outcomes
- There is no consensus on how "intensity of treatment" is to be defined
- Much overlap exists in approaches that are identified as having different underlying philosophies and practical applications
- The fidelity of treatment has typically not been measured
- Studies have not documented and accounted for variables outside of the intervention package that is the object of study (pp. 199-200)

Increasingly, researchers are advocating the use of multiple, systematic approaches to meet the needs of children with autism rather than touting a single approach as "the only" approach (Simpson, 2001; Strain, McGee, & Kohler, 2001). The literature is not definitive in demonstrating that children with autism require a particular array of services. Many strategies that are effective for children with autism are also effective with children with other types of disabilities as well as children without disabilities (Strain et al., 2001). Freeman (1997) offers eight guidelines for evaluating intervention programs for autism:

1. Approach any new treatment with hopeful skepticism. Remember the goal of any treatment should be to help the person with autism become a fully functioning member of society.

2. Beware of any program or technique that is touted as effective or desirable for every person with autism.

3. Beware of any program that thwarts individualization and potentially results in harmful program decisions.

4. Be aware that any treatment represents one of several options for a person with autism.

5. Be aware that treatment should always depend on individual assessment information that points to it as an appropriate choice for a particular child.
6. Be aware that no new treatment should be implemented until its proponents can specify assessment procedures necessary to determine whether it will be appropriate for an individual with autism.
7. Be aware that debate over the use of various techniques are often reduced to superficial arguments over who is right, moral, and ethical and who is a true advocate for the children. This can lead to results that are directly opposite to those intended, including impediments to maximizing programs.
8. Be aware that often, new treatments have not been validated scientifically. (p. 647)

This chapter has been broken into three sections. Section one provides a review of the literature on specific strategies that have been advocated to treat and/or educate children with autism; section two provides a review of the literature on general approaches that have been used widely with children with all types of disabilities, including autism; and section three describes the perceptions of Virginia's stakeholders regarding the efficacy of the approaches.

SPECIFIC APPROACHES

This section describes the efficacy of 14 "specific approaches" to educating and treating children with autism. These approaches are ones that are currently promoted for children with autism, although many are also used with children who have other types of disabilities. Information in this section is based on a preliminary review of the literature.

Applied Behavior Analysis (ABA)

Description of the Approach

The focus of Applied Behavior Analysis (ABA) is on developing skills to improve adaptive functioning by decreasing behavioral problems (e.g. tantrums) and increasing skills (e.g. communication). It is based on operant conditioning and uses a system of rewards, punishments, or neutral attention to change behavior (Mandlawitz, 1996). ABA focuses on objectively designed, observable behaviors and seeks to improve the behaviors using scientific methods. Each ABA program is designed to teach skills that fill the deficits of the individual child. Reinforcement and punishment are likewise designed to match the preferences of each child (Janzen, 1996).

In brief, the sequence of one of the most commonly cited ABA programs (i.e., discrete trial training) is SD—Prompt—Response— Consequence—Inter-trial Interval—Measurement.

In discrete trial training a child is given an S^D (student direction) such as, "Pick up the toys." The S^D is followed by a verbal, gestural, or physical prompt if necessary. The child then responds by either picking up the toys or not. The teacher follows the response with a consequence, which is rewarding, punishing, or neutral to the child. The belief is that behaviors that are reinforced are likely to occur again and behaviors that are not reinforced or are punished are not likely to occur again. After the consequence a 2-3 second inter-trial interval is observed where nothing happens. This is what makes the trials "discrete." Generally those administering the ABA session use this interval to record data for objectively measuring progress—the final step in the ABA sequence (Cassalles, 1997; Lovaas, 1993; Smith, 2001).

Although discrete trial training is the form of ABA that has gained notoriety, it should be noted that the tenets of ABA form the basis of many other approaches to educating children with autism (Heflin & Alberto, 2001a; Simpson, 2001). ABA has a range of applications. Most recently in the literature, the elements of ABA have been discussed in relationship to creating supportive classrooms and structured learning environments (see Heflin & Alberto, 2001b), language development (see Ogletree & Oren, 2001), functional communication training (see Durand & Merges, 2001), social relationships and social skills (see Sasso, Garrison-Harrell, McMahon, & Peck, 1998; Strain & Schwartz, 2001), incidental teaching (see McGee, Morrier, & Daly, 1999), and academic instruction (see Dunlap, Kern, & Worcester, 2001).

Efficacy of the Approach

ABA is without doubt the most intensively researched approach for educating children with autism. The literature on ABA spans a period of 40 years and includes program evaluations, empirical studies, replications of empirical studies, and literature reviews (Heflin & Alberto, 2001a). Although most of the empirical data have focused on discrete trial training (Smith, 2001), research has also addressed the efficacy of other models of instructional delivery that incorporate essential components of ABA or are used in combination with ABA. Some of the positive outcomes for children who receive ABA include increased IQ scores (Lovaas, 1987; McEachin, Smith, & Lovaas, 1993; Sheinkopf & Siegel, 1998), language skills (Smith & Lovaas, 1998; Smith, Eikeseth, Klevstrand, & Lovaas, 1997; Young, Krantz, McClannahan, & Poulson, 1994), social skills (Smith & Lovaas, 1998; Smith et al., 1997), imitation skills (Young et al., 1994), and adaptive skills (Epstein, Taubman, & Lovaas, 1985; Smith & Lovaas, 1998).

Despite the tremendous research base on ABA, its use has resulted in widespread controversy in recent years. Concerns about ABA include 1) the amount of time devoted to ABA instruction (particularly discrete trial training), 2) the use of ABA in isolation versus in combination with other techniques, 3) the manner in which personnel are trained and employed to provide ABA, and 4) claims regarding the outcomes ABA produces (Heflin & Simpson, 1998).

Although Lovaas (1987) demonstrated effective outcomes for children with autism who received discrete trial training for 40 hours a week, no empirically validated studies support the need for this level of time intensive training (see Heflin & Simpson, 1998 and Smith, 2001 for a discussion). Smith (2001) suggests that decisions about the amount of time devoted to ABA should consider the child's learning style, skill level, and age.

Increasing evidence suggests that ABA is most effective when used in combination with other instructional strategies (e.g., incidental teaching, priming, activity schedules, script fading, time delay) (Heflin & Simpson, 1998; Smith, 2001). The limitations of using only one approach, such as discrete trial training, are that it creates dependency on adults for instructional cues, children do not necessarily generalize skills learned in one setting to other settings, and the approach requires an intensive commitment of time to implement.

Decisions regarding the amount of time children receive ABA and whether ABA is used in conjunction with other techniques have implications for the manner in which staff are trained and employed in instructional settings. Schools are receiving increasing numbers of requests from parents for ABA trained teachers to provide intensive one-on-one training for their child throughout the entire school day (Heflin & Simpson, 1998; Simpson, 2001). These requests are often justified by parents on the grounds that ABA is the only empirically proven approach to educating children with autism. Additionally, it has been suggested that ABA may cure autism in some children (Lovaas, 1987).

While the efficacy of ABA is widely acknowledged, a number of researchers believe that it is not appropriate for every child (McClannahan & Krantz, 2000; Rimland, 1999; Simpson, 2001; Smith, 2001). Increasing evidence supports the need for educational programs that meet the individual needs of the child (Heflin & Simpson, 1998; Smith, 2001). There is no reliable evidence at this time to suggest the exclusive use of any one intervention program, including ABA (Simpson, 2001). At the same time, ABA remains an empirically sound approach to teaching children with autism.

Auditory Integration Training (AIT)

Description of the Approach

Auditory Integration Training (AIT) was developed in France by Guy Berard. It came to international recognition after publication of the book, *The Sound of a Miracle* in which Annabel Stehli described her daughter's improvement after AIT (Stehli, 1991). AIT is a treatment that purports to reduce the symptoms of autism by having a child listen to computer modified music through headphones. Proponents of AIT believe that it can lessen the tendency for people with auditory processing problems to shut out irritating sounds by teaching them to hear various frequencies. Through a 10-day program of two, 30-minute sessions each day, AIT trains individuals to hear all frequencies more evenly. People trained to administer AIT use electronically modulated music that has been individually designed to meet the needs of the particular child. The child listens to unpredictable music through headphones hooked to a machine that randomly selects high and low frequencies and may filter certain sounds.

The benefits that are attributed to AIT include (Edelson et al., 1999):

- Improved attention span, especially to auditory stimuli
- Improved memory, comprehension, and articulation

- Increased interest in communication
- Reduced perseverative behaviors
- Increased socially appropriate behaviors
- Reduced hypersensitivity to sound
- Reduced irritability, yelling, and temper tantrums
- Reduced lethargy and restlessness

Efficacy of the Approach

AIT is a controversial treatment for autism. Researchers have obtained mixed results regarding its effectiveness. This may be due to inconsistent use of a control group within the research, a lack of standardization in measurement methods (including the availability of valid and reliable instrumentation), and difficulties determining competing factors contributing or detracting from observable changes. In addition to the variability in findings regarding efficacy, some researchers also cite concerns that the treatment may cause discomfort or permanent hearing loss (Mudford et al., 2000; Rankovic, Rabinowitz, & Lof, 1996; Thibodeau et al., 1995), the theoretical basis for the technique is inconsistent with accepted knowledge about the auditory system (Tharpe, 1999); the cost of the treatment is high (i.e., about $2,000) given its uncertain benefits (Mudford et al., 2000); and interpretations of the treatment's effectiveness may be inaccurate (Howlin, 1997).

Rimland and Edelson (1995) conducted a pilot study where eight children with autism received AIT and nine listened to unprocessed music. Those receiving AIT were reported by parents to have improved attention and decreases in repetitive behavior, hyperactivity, and irritability. In a similar study Edelson et al. (1999) provided nine adults and children with AIT while 10 others received unprocessed music. Behavioral, electrophysiological, and audiometric measures were assessed prior to and following AIT. At the 3-month follow-up assessment there was improvement in the behavior (i.e., a significant decrease in the scores on the Aberrant Behavior Checklist) of the treatment group and one-third of the children showed improvement in the electophysiological task. Mudford et al. (2000) attempted to replicate the findings of Rimland and Edelson without success. Eight children with autism received AIT and eight were part of a control group. The researchers used measures of parent and teacher rating scales, IQ, language, and social/adaptive assessments. None of the children were found to benefit clinically or educationally from the treatment. Likewise, Bettison (1996) concluded that AIT was no more effective than a listening program of unaltered music and Gillberg et al. (1997) found that AIT had no impact on autistic symptoms.

Chelation Therapy

Description of the Approach

The US Navy first developed chelation therapy as a way of removing toxic metals from military personnel exposed to high concentrations of lead during the 1940's. Currently its use is being expanded to remove accumulated mercury from the bodies of children with autism. In theory once the heavy metals (such as mercury) are removed from the body, their toxic effects are eliminated and the individual begins to show improvement in the areas that were affected by the metals (Tilton, n.d.).

Mercury is a toxic metal that can cause immune, sensory, neurological, motor, and behavioral dysfunctions similar to traits associated with autism. Thimerosal, a preservative frequently added to childhood vaccines, has become a major source of mercury in human infants and toddlers. A review of medical literature and U.S. government data indicates that many cases of autism, in which an extended period of developmental normalcy is followed by an emergence of symptoms, are induced by early exposure to mercury. This type of autism represents a unique form of mercury poisoning (Bernard et al., 2000).

A physician should closely monitor this therapy. An ideal course of chelation therapy for mercury poisoning should include the following (Holmes, 2000):

- Stop ongoing exposure to mercury by eliminating fish or seafood from the diet, replacing any amalgam fillings in teeth with white composite material, and using only thimerosal-free vaccines.
- Get rid of the loosely-bound body mercury through medication.
- Chelate the more tightly-bound mercury including that in the brain through medication.
- Provide appropriate nutritional support to counteract mercury's known effects and to make the patient more comfortable while mercury is being moved around.
- Monitor the results through testing.

Efficacy of the Approach

A review of four databases (Medline, PsychInfo, ERIC, Lexis-Nexis) revealed numerous articles on chelation. None of these articles addressed the efficacy of chelation as a treatment for autism. Although articles from two internet web sites indicated that chelation had a positive effect on some individuals with autism (Autism Research Institute, 2001; Holmes, 2000), neither website provided sufficient information about the study methodology or findings to substantiate the claims of effectiveness.

Facilitated Communication (FC)

Description of the Approach

Facilitated communication (FC) is a method that offers physical and emotional support to enable an individual to communicate by typing on a word processor, letterboard, picture overlay, or other augmentative communication device. FC is a means of supporting written/typed communication. A facilitator offers emotional and physical support to help an individual with autism (or other disabilities) express him or herself by typing or pointing to letters, pictures, or other symbols (Janzen, 1996).

Physical support to the hand, wrist, arm or shoulder helps the learner focus and control extraneous, repetitive and impulsive movements. The facilitator slows and inhibits movements so that the communicator must put forth considerable and deliberate effort to point to a specific letter, picture, or symbol to communicate a message (Janzen, 1996). The person facilitating communication provides backward pressure (i.e., pulls the person's hand away from the communication device) but does not physically assist the individual to lower his or her hand downwards towards the symbol. Fading physical support is always a goal for individuals using this technique (Sabin & Donnellan, 1993).

Efficacy of the Approach

FC has been viewed as both an exciting and controversial technique since it was introduced in the United States in the early 1990's (Kerrin, Murdoc, Sharpton, & Jones, 1998). Proponents contend that FC allows individuals with severe disabilities such as autism to demonstrate unexpected, and sometimes remarkable, communication and literacy skills (Myles, Simpson, & Smith, 1996). In some cases, individuals with severe disabilities have reportedly communicated on advanced topics such as history, science, politics and business, and demonstrated social, intellectual, and literacy communication far beyond what professionals assessed to be their capacity (Myles, Simpson, & Smith, 1996).

Published support for FC is often anecdotal and descriptive in nature (Kerrin et al., 1998). Case studies and informal reports suggest that specific behavioral observations during FC indicate that participants in facilitation are producing valid communicative typing. These behaviors include making consistent typographical errors and producing phonetic or invented spellings considered unique to the individual with autism (Biklen, 1997; Jacobson et al., 1994; Myles, Simpson, & Smith, 1996). The technique allows an individual to communicate in a sophisticated manner, which then leads to increased self-esteem, cognition, and learning (Biklen, 1990). Some individuals who initially required full physical support at the hand are now reported to be able to type with a facilitator sitting next to them, but without touching them (Biklen, 1997).

Despite widespread anecdotal support for FC, its validity has been widely questioned. Critics have cited a lack of empirical evidence to support the technique, lack of a theoretical basis, few methods to determine authorship of the communication, and a negative impact on families who are accused of abuse through facilitated messages (Kerrin et al., 1998). The major debate surrounding FC is whether facilitators are physically influencing the message being communicated by the person with autism. Several empirical studies conducted to validate FC have failed to demonstrate accurate communication by a student when their facilitator was prevented from seeing the communication board or did not have knowledge of the answer to the question posed (see Eberlin, McConnachie, Ibel, & Volpe, 1993; Green, 1994; Myles & Simpson, 1994; Smith, Haas, & Belcher, 1994; Vazquez, 1994). Although these studies have been criticized for the formality of the testing situation, other studies regarding authorship that have occurred in more natural settings have also failed to support the legitimacy of the communication technique (see Bligh & Kupperman, 1993; Kerrin et al., 1998). Although anecdotal evidence exists to support the benefits of FC for some children, empirical studies clearly question the efficacy and legitimacy of the approach.

Floortime

Description of the Approach

Floortime is an intensive, person-centered, relationship-based approach that stresses the importance of developing empathy for and a belief in the ability for individuals with autism to express attachments in typical fashions (Klaw, 1997). Dr. Stanley Greenspan developed the approach seeing social connection as the key to global development since social connection affects communication, cognition, and play skills. Greenspan (1998) explains that stereotyped behaviors are soothing and can help a child with autism regulate him or herself. At the same time, stereotypes may isolate the child and prevent relationships with other people. Through Floortime children learn new activities that gradually replace their stereotypes. The expansion of a child's repertoire of behaviors allows social interaction, communication and other skills to develop.

Through home-based services, families and therapists use Floortime to facilitate affect, attachment, bonding, and a sense of relatedness for the child with autism (Klaw, 1997). Ideally, a trained therapist visits the home to work with the child and family at least weekly. Parents and other family members are asked to play with their child, using Floortime techniques, for 20-30 minutes in six to ten sessions per day for a total of two to five hours each day. To begin with, a Floortime therapist or family member uses a child's preferences and stereotyped behaviors in imitation to help the child develop interaction skills. For example, a therapist observes that a child spins from one corner of the room to another. The therapist follows, also spinning. Eventually the child waits for the therapist before spinning off again—initiating a "follow the leader" game (Klaw, 1997). The therapist then introduces similar, more functional activities to help the child organize him or herself while increasing interactions with others (Greenspan, 1998).

Floortime advocates criticize other intervention approaches for promoting isolated, unrelated skills or splinter skills that fail to engage the child in spontaneous pleasurable relationships (Heflin & Simpson, 1998). Greenspan maintains that by failing to engage the child in relationships, other approaches serve to intensify the child's difficulties and differences (Greenspan, 1992a).

Efficacy of the Approach

Although the efficacy of Floortime is supported primarily through testimonials (Heflin & Simpson, 1998), there are some studies to support positive outcomes. A 1997 analysis of the outcomes of 200 children who received Floortime (Greenspan & Wieder, 1997) found that 58% of the children demonstrated "very good outcomes". These outcomes included improved problem solving, purposeful interactions, and spontaneous verbal communication. Case studies published by the National Center for Clinical Infant Programs (see the October/November 1992 issue of *Zero to Three*) and Greenspan (1992b) support these findings. Attempts have been made to compare the effectiveness of Floortime with an adult directed approach (DeGangi & Greenspan, 1997). Although the outcomes favored Floortime, participants were not specifically identified as having autism spectrum disorders. Anecdotal reports and research provide support for Floortime as a promising technique for enabling children with autism to build relationships. Although negative research could not be located to dispute these findings, additional empirical studies are needed.

Picture Exchange Communication System (PECS)

Description of the Approach

PECS, created by Andrew Bondy and Lori Frost, teaches children to initiate communication within a social context. Through PECS children learn to locate a communication partner, present a picture of a desired item (or an object that represents the desired item), and obtain the item in exchange for the picture/object. There are no prerequisite skills for learning this communication technique. PECS is individualized for each child and is based on child selected preferences (Bondy & Frost, 1994). There are six phases of PECS:

- Phase 1: The basic exchange (i.e., exchanging a picture for a desired item) is initially taught by two adults. With physical assistance from one adult, the child places a picture/object of a desired item in the other adult's hand. No verbal cues or reminders are given. Once the picture has been received, the child is given the requested item or activity from the adult who received the picture request. This might be a hug, toy, snack, drink, or other preferred item or activity.

- Phase 2: The teacher helps the child expand spontaneity by teaching him or her to locate a partner and persist in getting attention to receive his or her requested item or activity. Phases one and two generally are accomplished within a few days.

- Phase 3: The child is taught to select a picture from an array of two or more pictures. The child's vocabulary is expanded to 12-20 words that he or she can use to make requests. This takes several days to months to accomplish.

- Phase 4: The child is taught to build sentence structure with an "I want" picture/word card. The "I want" card is paired with a picture so that the child may request items that might or might not be present. The child's vocabulary is expanded to 20-50 pictures and emphasis is placed on communicating with a variety of partners.

- Phase 5: The child is taught to respond to the question, "What do you want?" using the "I want" picture and the 20-50 pictures of familiar, preferred items. Phases four and five are generally mastered within a few weeks.

- Phase 6: Students learn to comment in response to the question, "What do you see?" with an "I see card." At this point the child has 30-50 picture cards and two sentence starter cards in his or her vocabulary.

Beyond phase six, the goal is to increase vocabulary, language, and sentence structure to include more people and settings. PECS provides a communication system and opportunities for the individual to have his or her wants and needs met. Often behavioral issues are alleviated because the individual does not have to use challenging behaviors to communicate (Bondy & Frost, 1994).

Efficacy of the Approach

In their original study of 85 children (all under age 5) who lacked a functional communication system, Bondy and Frost (1994) reported that over 95% learned to exchange two or more pictures. For 66 children who used the system for more than a year, 59% acquired speech as their only method of communicating, and 76% used either speech or speech in combination with the picture system to communicate. At this time there are no substantial data to indicate the development of speech for children above age six who use PECS (Bondy and Frost, 1998).

While few studies have replicated the Bondy and Frost (1994) findings, anecdotal reports support this alternative and augmentative model for teaching children with autism to communicate. In a review of the literature on intervention options, Heflin and Simpson (1998) conclude that "PECS is an empirically sound method that has excellent utility in developing communication skills in both nonverbal students with autism and limited communication students with autism . . . [and that it] is particularly well organized and consumer friendly" (p. 198). Clearly additional research is needed to demonstrate the efficacy of this promising approach.

Play Therapy

Description of the Approach

The old school of play therapy uses play as a substitute for verbal exchanges. Play reduces resistance so that the individual can benefit from psychological counseling to work through conflicts. The theory is that the child represents the inner conflicts through his or her play (Axline, 1947; A. Freud, 1946; Klein, 1955). This type of therapy is still practiced, but is seen as less effective for children with autism than the newer thinking on play therapy (Wolfberg, 1999).

The new thinking regarding play therapy suggests that children with autism need to be taught to play and their lack of play skills keeps them from learning social and communicative skills. Integrated play (one new method of play therapy) strives to teach the child with autism how to play through "guided participation" (Rogoff, 1990). Children with autism are involved in play activities with socially competent peers while supported by an adult. The goal is for the whole group to have fun, while expanding the child's with autism social and symbolic play skills. Proponents of integrated and guided play suggest that it will help children with autism develop relationships, improve social skills, and increase language skills (Wolfberg, 1999).

Efficacy of the Approach

Limited information was located on the efficacy of play therapy for children with autism. Much of the literature describes methods for providing play therapy for children with autism and other special populations (see Hellendoorn, van der Kooij, & Sutton-Smith, 1994; Landreth, 2001; Mittledorf, Hendricks, & Landreth, 2001) or articulates how children with autism play (see Matthews, 1998; vanBerckelaer-Onnes, 1994). Within this literature professional experiences are shared regarding the effectiveness of play therapy in promoting social skills and relationships. Data-based research articles were not located in this preliminary review of the literature.

Social Communication Emotional Regulation and Transactional Supports (SCERTS)

Description of the Approach

SCERTS is an eclectic model that incorporates a variety of best practices for the assessment and treatment of young children (i.e., under age 6) with autism. It recognizes that autism is a spectrum disorder and that each child with autism has varied needs. This model is strongly family-centered and draws from developmental, social, and behavioral approaches. The approach was originally developed by Barry Prizant and Amy Wetherby. Both individuals are speech-language pathologists who have worked with young children with autism for many years.

Efficacy of the Approach

Dissemination of information about the SCERTS model of intervention has been limited to one book (see Wetherby & Prizant, 2000) and presentations throughout the country. Empirically-based research on the effectiveness of the approach was not located during a review of the literature.

Secretin

Description of the Approach

Secretin is a naturally occurring hormone that is found in the pancreas, liver, and upper intestinal tract. It stimulates the pancreas to release bicarbonate and digestive enzymes into the intestinal tract, it stimulates the liver to excrete bile, and it stimulates the stomach to produce pepsin. Secretin is also found in the brain and stimulates the production of serotonin (Beck, Beck, & Rimland, 1998).

At this time the use of secretin is considered to be a nonstandard or alternative intervention for treating autism. The treatment involves giving intravenous injections of secretin made from pigs (Edelson, n.d.). The reported benefits of secretin include improved speech/language, eye contact, sleep, attentiveness, and behavior (Edelson, n.d.b; Horvath et al., 1998).

Efficacy of the Approach

Much of the available information on secretin is from anecdotal reports from parents rather than scientific inquiry. Those studies that do exist tend to rely on data obtained from a small number of children. Horvath et al. (1998) reported that three children (with autism and chronic diarrhea) who received secretin during endoscopy showed improvement in gastrointestinal symptoms, eye contact, alertness, and expressive language. In contrast, a study by Richman (1999) found no substantial behavior changes from secretin when standardized assessments and direct observational data were used to evaluate its effectiveness with one child.

Repligen Corporation recently released the results from a three-dose, double-blind, randomized, study on the effects of the hormone (see Rimland, 2001). Children with autism between the ages of three and six were administered secretin while others received a placebo. Preliminary study findings suggest significant improvement in children with gastrointestinal symptoms and moderate to severe autism symptoms; however, ratings of these children using the Childhood Autism Rating Scale (CARS) showed no improvement. Additional studies are currently underway to determine whether 1) secretin benefits children with certain autism symptoms, 2) biological secretin is more or less effective than a synthetic version, or 3) varying the dose makes any difference (Bristol-Power, 2000).

Researchers have voiced several concerns about this treatment. First, some medical professionals believe that children may develop immunity to the pig secretin which would then cause them to reject their human secretin (Richard, 2000). This has serious implications. Since using secretin has increased seizures in some children with autism (Richard, 2000), a group that already has a greater than normal seizure rate, its use must be questioned for all children. Medical professionals have voiced their concerns because the side effects of prolonged use are unknown and the best candidates for use and the dosage are also unknown. Thus, the use of secretin to treat children with autism needs continued thorough and controlled investigation.

Sensory Integration

Description of the Approach

Sensory integration refers to the integration and interpretation of sensory stimulation from the environment by the brain (Hatch-Rasmussen, 1997). Much of the sensory integration literature is grounded in the work of Jean Ayres, an occupational therapist and pioneer in developing theories on sensory dysfunction. She defines sensory integration as the organization of sensation for use. Individuals with poor sensory integration may have difficulty completing tasks, learning, processing, coordinating movements, and organization. Sensory problems include atypical reactions to common sensory experiences. An individual may be overly sensitive or not sensitive enough to sounds, sights, touch, movement, body position, or deep pressure. Poorly integrated sensory system(s) may lead to isolation, irritability, distractibility, hyperactivity, frustration, aggression, and a lack planning on the part of the individual (Ayres, 1979/1995). This theory is further supported by reports from well-known adults with autism such as Donna Williams, Temple Grandin, and Georgiana Thomas. These adults talk about their own struggles with hypersensitivity, hyposensitivity, seeking and avoiding specific sensations, and how they have learned to understand and respond to these sensations and control their own behaviors in response to sensory information.

An individually designed sensory integration program responds to a child's sensory needs or deficits while increasing tolerance to offensive stimuli and satisfying sensory cravings. An occupational or physical therapist generally prescribes evaluation and treatment. Treatment is designed to help organize the central nervous system to provide sensory information to the child with integration difficulties (Hatch-Rasmussen, 1997). This assists the individual with inhibiting or modulating sensory information and processing a more organized response to sensory stimuli (Ayres, 1979/1995). The benefits of appropriately designed sensory integration exercises include an increased ability to process sensory information and decreases in problematic and/or stereotypical behaviors (Kientz, 1996).

Efficacy of the Approach

Sensory integration has been used to address the needs of children with autism, children with other types of disabilities (e.g., learning disabilities, mental retardation, developmental delays), and children at-risk. Controversy exists regarding the effectiveness of the treatment and the credibility of existing research. Griffer (1999) points out that much of the empirical research on sensory integration has been criticized (by researchers) for the methodology employed (e.g., statistical analyses chosen, presence of confounding variables, lack of a comparison of sensory integration to other treatment methods). These criticisms make it challenging to draw interpretations regarding the efficacy of sensory integration.

In her review of the literature, Mauer (1999) found many studies (see Ayres, 1972a/1972b/1978; Ayres & Mailloux, 1981; Magrun, Ottenbacher, McCue, & Keefe, 1981; Ottenbacher, 1982; Ray, King, & Grandin, 1988) that support the impact of sensory integration therapy on behavior. Some of the benefits of therapy included "improved ability to organize responses to the physical environment, increased language and reading development, improved social interactions and play, and increased ability to attend to the task or maintain emotional control under stress" (Mauer, p. 389). Therapy leads to improvement in motor skills, cognition, language, and academic skills.

While the literature appears to support the benefits of sensory integration when used in isolation or in combination with other techniques, additional research is clearly needed to confirm the findings of previous studies and address their existing limitations. Most of the research located for this review was conducted several years ago, thus supporting the need for new, updated research on the approach.

Social Stories

Description of the Approach

Social stories were developed by Carol Gray as a strategy to provide social information for individuals who experience difficulty understanding social cues and rules. A "social story" is a short story that describes relevant social cues and common responses, providing a student with accurate and specific information regarding what occurs in a situation, why it occurs, and how the student should respond in the situation (Gray, 1994, 2000). The complexity of the story should reflect the student's abilities and learning style. Pictures and written text are often used. Social stories can help individuals understand day to day situations such as completing work, waiting in line, or being quiet when the teacher is talking. Social stories can also assist children to understand and prepare for non-routine situations such as field trips and fire drills. This is an example of a social story:

Working Quietly

Usually the students need to be quiet during work time.
The teacher is happy when the students are quietly doing their work.
I am one of the students.
I have work to do.
I will try to do the work quietly that the teacher assigns.

Social stories have been used with a variety of children who have varied social and behavior challenges. Initially they were used primarily with children who were considered to be "high functioning", but the guidelines have been modified to fit the needs of those with more severe disabilities. Increased understanding of social cues and rules may alleviate behaviors that occur due to a lack of social understanding. Improved social skills relate to an improved ability to communicate, function in daily routines, learn, and socialize (Gray, 1994, 2000).

Efficacy of the Approach

While there are numerous anecdotal reports to support the benefits of social stories, few research studies have been conducted. One study of three children (Swaggart et al., 1995) used social stories along with traditional social skills training to produce changes in student behavior. Within 10 to 18 days, the use of social stories decreased the students' challenging behaviors (e.g., hair pulling, scratching, grabbing, screaming) and increased their use of more appropriate behaviors. Gray and Garand (1993) note that for many students, social stories have been effective in improving their behaviors to social situations within a relatively short period of time.

Another study (Kuttler, Smith Myles, & Carlson, 1998) evaluated the effectiveness of two social stories to reduce the precursors to tantrum behaviors (e.g., screaming, swearing, dropping to the floor) in a student with autism. Although several other interventions (e.g., schedules, stickers, pictures) were found to be ineffective in changing the child's behaviors, the use of social stories produced remarkable improvements in the child's behavior. The researchers concluded that some students may "require visual interventions along with directions, choices, or rationale . . .to manage their own behavior" (p. 181).

Gray and Garand (1993) have developed specific guidelines to help people write effective social stories. While additional studies are needed to fully determine the effectiveness of social stories across settings and levels of functioning, their use is easy to implement and can be tailored to meet a student's specific needs (Kuttler et al., 1998; Richard, 2000).

Special Diets

Description of the Approach

There are several diets that report success in diminishing symptoms of autism. For the purpose of this report, the focus is on two commonly utilized diets (i.e., Candida and Gluten-Casein Free). All diets should be discussed with a physician prior to implementation, and monitored closely. Neither of these diets is easy; they require vigilance and commitment.

The Candida diet is one high in refined carbohydrates to boost the immune system. Yeast is naturally present in the human body; however, if candida albicans yeast multiplies into an overgrowth it releases toxins in the body. These toxins impair the central nervous system and the immune system. It is believed that some of the behavior and health problems seen in autism may be related to toxins released from the candida albicans yeast. With the Candida diet, the individual takes nutritional supplements such as acidophilus and/or antifungal medications such as nystatin, ketoconosal, or diflucan. The diet is low in sugar and limits foods in which yeasts thrive. By following the diet the yeast is destroyed and is secreted from the body. Proponents note a decrease in behavior and health problems and an increase in more appropriate behaviors after toxins have been secreted (Edelson, n.d.a; Rimland, 1988).

Another special diet used to treat autism is the Gluten-Casein Free (GFCF) diet. It is suggested that in some individuals with autism, gluten (from wheat, barley, oats, and rye products) and casein (from human or cow milk) are not completely broken down by the body. Some of the incompletely broken down components that are released into the bloodstream have morphine-like properties. These proteins are transported to the brain where they bind to receptors causing an effect that is manifested as the symptoms of autism (Lewis, 1998). The diet begins initially by removing casein (dairy) from meals and snacks. Changes occur to the individual's diet one meal at a time, sometimes starting with breakfast and then adding other meals until all are structured around the diet. Next gluten is removed from the diet. Once the diet is composed of gluten and casein free foods, the child must be carefully observed (Tilton, n.d. b, Seoussi, 2000). Benefits attributed to the GFCF diet include decreased self-injurious behavior, improved behavior, increased speech, and lessening or elimination of symptoms associated with autism (Seroussi, 2000).

Efficacy of the Approach

Diet related treatments are not a new phenomenon. Recently, however, several treatments have come to the forefront to address the biochemical neurological aspects of autism and offer approaches to autism from a chemical perspective. Much of this information has been anecdotal and frequently resulted from changes in autism characteristics while treating other presenting problems.

Several research studies were located on the gluten-casein free diet. Cade et al. (2000) found that 81% of the children with autism who received a gluten-casein free diet showed improvement within 3 months of beginning the diet. In contrast, Spoonheim (1991) and Vlissides (1986) found no improvement in individuals who received a gluten-free diet. It has been hypothesized that the lack of improvement in the latter two studies may be because casein was not simultaneously omitted from the diet. Research on the efficacy of the Candida diet was not located following a search of the Medline database.

A preliminary review of the research literature on special diets suggests that this treatment is effective with some children with autism spectrum disorders. Although controversial side effects of the diets were not mentioned in the sources consulted, the literature remains inconclusive regarding the benefits of special diets, and additional research is clearly needed to drawn conclusions regarding the efficacy of these approaches. Current research is focusing on studies to "empirically support or refute anecdotal stories regarding remarkable changes in individuals with autism through intervention with vitamins, diet, and medication" (Richard, 2000, p. 137).

TEACCH/Structured Teaching

Description of the Approach

TEACCH stands for "Treatment and Education of Autistic Children and related Communication Handicapped children" and was developed in North Carolina by Dr. Eric Schopler as a system of support for North Carolina residents. The TEACCH method relies on structured teaching and the principles of applied behavior analysis (ABA) to enhance skills and improve the individual's ability to adapt while accepting existing deficits (Mesibov, n.d.). The terms "TEACCH" and "structured teaching" are often used interchangeably.

TEACCH focuses on arranging the environment and developing supports to offer teaching in a logically structured manner. Some of the techniques used include visual presentation of information and materials, working from left to right and top to bottom, "finished" boxes, routines, and teaching skills across a variety of settings. For example, a student might be assigned a study carrel in which to work. On the left side of his or her carrel is a series of boxes. In each box there is one work task. After the student completes the work task, he or she returns the completed work to the original box or folder and puts the completed work in a "finished box". TEACCH advocates for a separate place for the individual with autism to play or relax versus completing work.

In North Carolina, TEACCH centers offer parent counseling and training; consultation to classrooms, group homes and other community agencies; and training on diagnosis, assessment, structured teaching, educational, residential and vocational services, and parent involvement. Virginia residents (and others) can participate in training, visit a TEACCH center for a diagnosis of autism or consultation as space at the Center allows (Marcus, 1996, Mesibov, n.d.).

Efficacy of the Approach

Proponents of this technique believe that the structure and routine of the TEACCH model enables the student to maximize benefits from his or her educational program while increasing independence (Mesibov, 1998). Through the completion of work tasks, individuals with autism achieve greater independence in structure, communication, social behaviors, functional academics, independent living skills, motor skills, work behaviors and community skills (Marcus, 1996).

A recent study by Ozonoff and Cathcart (1998) evaluated the effectiveness of a TEACCH-based home intervention program for young children with autism. Results indicated that all of the children in the treatment group made significant improvement on four of the seven assessment sub tests and improved on all of the sub tests compared to the no-treatment group. The treatment group made an average developmental gain of 9.6 months. Panerai, Ferrante, and Caputo (1997) also found the TEACCH principles to be effective when they conducted a pilot study with 18 children ages seven to 18 years who had severe and profound mental retardation and behavior problems (e.g., aggressiveness, self-injurious behavior, stereotypic behaviors). Statistically significant progress was noted in the areas of cognition, motor activities, and perception; stereotypic behaviors were reduced. They noticed an increase in behaviors during unorganized leisure time and a decrease during structured activities. Additionally, they noted increased attention, independence, and communication by the group. Both studies employed pre and post-tests to determine student skills prior to and after the TEACCH intervention.

While several earlier (1970s and 1980s) data-based studies show the effectiveness of the TEACCH program, a review of the literature shows a lack of recent studies about TEACCH's effectiveness. Smith (1996), a proponent of behavioral treatments (discrete trial training and ABA), often has voiced concerns about the lack of data-based research on the TEACCH program. He contends that "little scientific evidence exists to show that such classes [TEACCH, full inclusion, etc.] are helpful (except when they rely on behavior-analytic teaching methods . . .") (p. 48). While indeed there should be more research about the program's effectiveness, it is difficult to compare this eclectic model of TEACCH, which incorporates a variety of techniques, with a single technique such as ABA.

Vitamin Therapy

Description of the Approach

A variety of vitamins have been employed to treat autism. Vitamin A, vitamin B6 given with magnesium, vitamin C, and dimethylglycine (DMG), have all been mentioned as potentially beneficial in alleviating symptoms of autism that may be caused by a deficiency. Vitamin therapies help to correct the deficiencies (Rimland, 1987). It is recommended that all vitamin therapies be discussed with a physician prior to use.

- Natural Vitamin A may reconnect the retinoid receptors critical for vision, sensory perception, language processing and attention.

- Vitamin B6 is involved in protein metabolism, red blood cell metabolism, and making hemoglobin within red blood cells to carry oxygen to tissues. The nervous and immune systems need vitamin B6 to function efficiently. Vitamin B6 helps maintain blood sugar within a normal range (National Institute for Health, 2001). For maximum benefit, B6 needs to be taken with magnesium.

- Vitamin C is a safe substance which is beneficial to the brain and body. Vitamin C is important to brain function. The earliest signs of vitamin C deficiency are confusion and depression. By augmenting the diet with a daily dose of Vitamin C individuals may experience improvement in cognition and the alleviation of confusion and depression (Rimland, 1998).

- Amino Acids such as Dimethylglycine (DMG) help the body break down certain types of food substances. DMG is classified as a food, not as a vitamin as there are no specific symptoms associated with a deficiency of DMG.

Efficacy of the Approach

Recent attention has been given to the use of Vitamin A in children with autism. Although no empirical data were found to support this approach, Megson (1999) reported that Vitamin A in its natural form, such as cod liver oil, helps to rebuild receptors in the brain that affect vision and speech. Vitamin A therapy may result in increased sociability, language, and eye contact. Empirical data substantiating this claim were not located during an initial review of the literature.

Research on the effectiveness of vitamin B6 with children with autism began in the 1960's. Rimland (1994) reviewed 18 studies published from the 1960's to the early 1990's in which all studies yielded positive results for some individuals with autism. Approximately half of the participants did not benefit from B6. None were adversely affected by the mega doses of B6 (Rimland, 1996). Benefits of B6 therapy for children with autism include better eye contact, less self-stimulatory behavior, more interest in the world, fewer tantrums, and increased speech (Rimland, 1987, 1996a, 1996b).

DMG is reported to benefit some children with autism. Increased speech and eye contact are the most frequently noted changes in those children helped by DMG; however, behavioral improvement, including decreased frustration, is also reported (Rimland, 1996a; Rimland, 1996b). Parents have identified positive benefits in behaviors, which are often noticed within two weeks of using DMG.

Vitamin therapy appears to be a promising approach for some children with autism. A survey of over 8,000 parents (Rimland, 1994) found that twice as many children who received Ritalin demonstrated increased problem behaviors than those who noted improvements. In contrast, parents who employed vitamins and controlled diets reported improved behavior with few side effects. Despite these findings, the empirical data on vitamin therapy for children with autism are extremely sparse (Heflin & Simpson, 1998; Tolbert, Haigler, Wairs, & Dennis, 1993). Additional studies are needed to support claims of effectiveness and determine what factors enable some children to benefit from treatment while others do not. The long-term effects of vitamin therapy remain unknown.

GENERAL APPROACHES

This section describes the efficacy of six "general approaches" to educating children with autism. These approaches are ones that are currently promoted for children with a variety of disabilities, including autism. The approaches are typically not viewed as specific treatments for autism. Information in this section is based on a preliminary review of the literature. To the greatest extent possible, discussions regarding efficacy have focused on literature that specifically addresses the approach for children with autism.

Augmentative Communication

Description of the Approach

Using some means other than speech to communicate is referred to as augmentative and alternative communication (AAC) (Van Tatenhove, 1993). Augmentative communication is the use of aids that supplement existing communication skills, which might include pointing at pictures, typing, or gesturing. Alternative communication refers to the method that a person with no vocal abilities uses to communicate, for example American Sign Language, or a computerized speech synthesizer (Beukelman & Mirenda, 1992; Reichle, York, & Sigfoos, 1991).

There are three main parts to an AAC system: access, process, and output. Access refers to how the person using AAC creates the message(s). The individual may type, hand someone a picture, activate a dynamic picture display, or use another access method. Processes are how an individual increases speed and accuracy in using the system. Output refers to the message being transmitted to a communication partner (Beukelman & Mirenda, 1992). Output is generally transmitted visually—the partner looks at words, pictures, gestures, or signs and interprets the message; or auditorially—the partner hears a digitized or synthesized message from a device.

Many types of AAC devices are commercially available, including those with single message output (which have to be re-recorded frequently) to devices with almost unlimited message capability (Ravlin, 1997). PECS and facilitated communication (described earlier in this document) are both methods of AAC.

Efficacy of the Approach

Evidence spanning several decades is available to support the use of various forms of augmentative and alternative communication with children with autism. Most research on communication for children with autism has advocated concrete visual systems such as picture symbols or manual signing (Heflin & Alberto, 2001; Smith, 2001). Some of the forms of AAC supported in the literature on autism include photographs and line drawings (Bondy & Frost, 1994/1998; Mirenda & Santogrossi, 1985; Peterson, Bondy, Vincent, & Finnegan, 1995; Reichle & Brown, 1986; Schwartz, Garfinkle, & Bauer, 1998; Stiebel, 1999); computerized approaches (Panyan, 1984), sign language (Carr, Kologinsky, & Leff-Simon, 1987; Konstantareas, 1987), orthography (Biklen, 1990), and facilitated communication (Biklen, 1997; Jacobson et al., 1994; Myles, Simpson, & Smith, 1996). Beukelman and Mirenda (1992) note that individuals with autism benefit from the same AAC strategies as individuals with other disabilities. Selection of the method should match the needs of the child.

Most augmentative communication systems focus on expressive communication. However, natural aided language stimulation is a receptive language strategy in which the communicating partner touches pictures/objects/symbols on a communication board as the partner says the word. This strategy has received a great deal of attention recently and is supported through research (see Cafiero, 1998; Goosens, Crain, & Elder, 1992). Visual strategies (discussed later in this section) have also been found to enhance receptive communication.

Intensive Early Intervention

Description of the Approach

Early intervention refers to the collaboration of providers and families in developing and implementing services to young children (birth to 3 years) who have disabilities (Gallagher, LaMontagne, & Johnson, 1994). Specialized services might include occupational, physical, or speech therapy, special instruction, and service coordination (McWilliam, 1996). Developmental progress is enhanced by participation in early intervention (Bricker & Veltman, 1990). Bailey and Wolery (1992) suggest that early intervention should be composed of:

- Support to the family in achieving outcomes for their child and family
- Promotion of child engagement, independence and mastery
- Development in key domains
- Building and supporting the child's social competence
- Promoting generalized use of functional skills
- Preparation for normal life experiences

- Prevention of the emergence of future problems or disabilities.

Efficacy of the Approach

The benefits of early identification and early intervention services for children at-risk and with developmental disabilities are validated by a wealth of research. Mays and Gillon (1993) confirm that as with most developmental disabilities, when autism is recognized and interventions begin early, outcomes for children with autism are greatly enhanced. They further explain "when intervention begins early, children demonstrate better communication skills, fewer out-of-control behaviors, and their parents develop a greater understanding and acceptance of the disorder" (p.17).

Developmental patterns of young children with autism are both atypical and delayed. Since young children with autism do not follow typical developmental patterns in domains such as communication, social development, sensory processing, emotional development, and motor development, early intervention programs based on learning patterns of normal development may not be appropriate for these children (Rogers, 1999). Published studies of positive outcomes reflect what we know about how children with autism best learn. These programs, regardless of theoretical orientation, use effective practices featuring increased structure, increased adult directiveness, increased numbers of educational hours, and precise teaching methods combined with carefully designed curriculum (Rogers, 1999). These programs are designed very differently from typical early intervention programs that feature child-centered, play-based approaches.

Research also supports the view that integration of children with autism with typically developing peers can promote intellectual growth and social and interpersonal gains, as well as benefits to their normally developing classmates (Tomchek et al., 1992). Hurth et al. (1999) conducted a recent study to determine commonalities and differences in critical program practices among nationally known, validated educational programs for young children with autism. Program staff agreed on the use of early intervention, individualization, specialized curriculum, family involvement, systematic instruction, and intensity of engagement. The following program elements were determined important by some, but not all, of the programs: structured environments, developmentally appropriate practices, and interventions in settings with peers. These data are supported by earlier research conducted by Simeonsson, Olley, and Rosental (1987), who found that children with autism experienced more positive outcomes when they received early intervention services before age five, parents were trained to conduct programming at home, intensive instruction was provided across multiple settings, positive consequences were employed, and instruction was provided in natural settings with peers.

Inclusion with Non-Disabled Peers

Description of the Approach

According to the National Information Center for Children and Youth with Disabilities (1995), inclusion can be defined as: "The practice of providing a child with disabilities with his or her education within the general education classroom, with the supports and accommodations needed by that student. This inclusion typically takes place in the student's neighborhood school" (p. 3). Key to this definition is that inclusive education is more than physical placement in the general education classroom. Adequate special education services and supports must be provided to promote a child's success.

In inclusive settings, all children do not obtain the same level of understanding or knowledge in the course of a school year. However, all students must have access to the same information whether or not they reach similar goals (Downing, 1996). The concept of "partial participation" (Ferguson & Baumgart, 1991) supports the idea that participation in various learning activities will be realized differently by different students. Inclusive education emphasizes a variety of instructional strategies, modifications, and supports to meet the educational needs of each child.

Several individuals have made a differentiation between "full inclusion" and "partial inclusion" (Dymond, 2000). For some, inclusive education constitutes full time placement in general education classrooms with non-disabled peers. Others believe that inclusion can include instruction in both general and special education classrooms. Lack of consensus about the amount of time students must spend with their non-disabled peers in order to be "included" has presented barriers to comparing research studies that purport to evaluate the effectiveness of inclusive education.

Efficacy of the Approach

Strain, McGee, and Kohler (2001) cite an extensive number of empirical studies that dispel the notion that children with autism require one-to-one instruction in order to learn and that they must achieve behavioral compliance before they are ready to be included with peers. While studies do exist to support one-on-one instruction and the "readiness model", there is sufficient evidence to verify the effectiveness of instruction that is delivered in inclusive environments. It is not an issue of whether children with autism can benefit from inclusion, but whether appropriate supports have been put in place to support each child's inclusion (Strain, McGee, & Kohler, 2001). Physical integration in the general education setting, in and of itself, is insufficient to stimulate social interactions and learning (Myles, Simpson, Ormsbee, & Erikson, 1993).

Much of the empirical data on inclusive education for children with autism focus on young children (i.e., preschool and elementary school children). Existing research has demonstrated that children with autism can improve social skills (Strain & Kohler, 1998), play skills (Baker, 2000), and developmental levels (Harris, Handleman, Kristoff, & Gordon, 1990; Hoyson, Jamieson, & Strain, 1984) when educated with their peers without disabilities. Children who are included learn age-appropriate behaviors and form friendships that allow them to practice appropriate communication skills (Koegel & Koegel, 1995). Inclusive education also enables children without disabilities to develop positive attitudes toward their peers with disabilities (Strain & Cordisco, 1993; Strain & Kohler, 1998). These findings are consistent with the findings of studies conducted with children with other types of disabilities in preschool, elementary, middle, and high school settings (see Dymond, 2000 for a review of the literature).

Some have suggested that inclusive education may not be as effective for children with autism as it is for children with other types of disabilities (Mesibov & Shea, 1996). The literature on inclusive education has certainly demonstrated that it can be more effective, as effective, or less effective than other service delivery models (Dymond, 2001). Differences in the way schools currently define and implement inclusion may have more to do with the efficacy of inclusive education than the disability label of the child. Inclusive education is clearly a valid method for educating children with autism and other disabilities when appropriate special education supports and services are provided.

Music Therapy

Description of the Approach

Music therapy is the use of music to enhance one's personal life by creating positive changes in human behavior. Most people respond positively to some form of music (Boxill, 1985; Lubrano, 2000; Thaut, 1984). It also has a calming effect on some individuals with hyper-responsive central nervous systems (Toigo, 1994). Although musical skills are not necessary to participate in music therapy, the approach strives to actively engage individuals during therapy (Boxhill, 1985).

For individuals with autism, music is non-threatening and allows nonverbal teaching and learning (Boxill, 1985; Lubrano, 2000; Thaut, 1984). For example, a child with autism might rock back and forth. The music therapist could improvise music to match the tempo of the rocking. The therapist might also change the tempo of the music to encourage the child to increase or decrease the speed of his/her rocking to match the change in tempo (Lubrano, 2000). Used as a teaching strategy music may help the individual with autism (Boxhill, 1985; Lubrano, 2000):

- have greater interest in family and social relationships
- handle unpredictable social situations
- enhance communicative expression
- increase fine and gross motor control
- increase learning
- engage in varied, positive experiences
- increase motivation
- increase awareness of self, others, and the environment

Efficacy of the Approach

While music has been used since ancient times in religious ceremonies and to promote psychological and physical health, there are few data-based research studies to support the intervention with children with autism. A study by Wimpory, Chadwick, and Nash (1996) evaluated the technique with a three-year-old child with autism who did not communicate. According to the study, the child showed improvements in eye contact and initiated some social interactions once music therapy started. At a two-year follow-up, these skills were being maintained. Monroe (1996) also found music therapy to be beneficial. In an informal study of 20 children (five had autism), he compared children's responses to three conditions: no music, Comfort Zone music (i.e., music with regular rhythm and a tempo of 60 beats-per-minute), and Comfort Zone music plus Hemi-Sync®. (Hemi-Sync® is a specific form of music therapy developed by the researcher.) Seventy-five percent of the children made significant gains when they received a combination of Comfort Zone music and Hemi-Sync®. Monroe (1996) contends that the format contributes to long term changes in the child's ability to organize information.

Wilson and Smith (2000) undertook an extensive investigation of the music therapy literature to determine the types of populations music therapists assessed and the types of assessment instruments used in the school setting. Their survey found that 10% of those served were children with autism and that there was "little commonality in the assessment tools being used by therapists and researchers" (p. 95). For music therapy to be considered a viable intervention, the field must use standardized assessment tools so that studies can be replicated to demonstrate its effectiveness. At this time, one can rely only on a few data-based studies and many positive anecdotal reports from therapists and parents.

Positive Behavior Supports (PBS)

Description of the Approach

Positive behavior supports emphasizes a collaborative problem-solving approach to develop individualized interventions for persons who exhibit challenging behaviors. The focus of PBS is on preventing behavioral issues by teaching alternative (appropriate) behaviors that serve the same function as the challenging behaviors. The goals of PBS include helping individuals develop communication, social, and self-help skills; form positive relationships; and take an active role in their school and community (Janney & Snell, 2000).

With PBS, a functional behavioral assessment is completed to determine the purpose or function of the child's behavior. For example, the purpose of the behavior may be to obtain attention, retrieve something tangible (e.g., food, toy), escape or avoid something undesirable, or satisfy sensory needs. Following the assessment, a positive behavior support plan is designed to alter the behavior of those who interact with the child and to teach the child new skills to use that more appropriately get his/her needs met. The first part of a positive behavior support plan involves preventing the behaviors from occurring. This is done through changes in teaching strategies, accommodations, and modifications (Sailor, 1996). Secondly, the individual needs to learn functional skills that replace the behavior of concern (e.g. asking for help instead of throwing objects when help is needed). The third part of a PBS plan involves the development of reactive strategies. Reactive strategies are what all adults do when the problematic behaviors occur (Janney & Snell, 2000; LaVigna & Donnellan, 1986). These three components emphasize positive, non-aversive, person-centered approaches to addressing the needs of individuals with challenging behaviors.

Efficacy of the Approach

A tremendous amount of empirical evidence is available to support the use of positive behavior supports with individuals who have a variety of challenging behaviors and disability labels. PBS research that has been conducted specifically with children with autism spectrum disorders clearly documents the effectiveness of this strategy.

Schreibman, Whalen, and Stahmer (2000) investigated the use of video "priming" (i.e., previewing future events) to eliminate disruptive behavior in children ages three to six with autism spectrum disorders when they made transitions between activities (e.g., leaving the house, changing clothes). Prior to the intervention (video priming) the children engaged in tantrum behavior 60-70% of the time during transition. This behavior dropped to 0% for all children during the intervention and continued into post-treatment and follow-up. Each of the children also generalized the appropriate behavior to new transitions. A similar strategy (videotaped self-modeling) likewise was used to decrease challenging behaviors in three children (ages seven to 12) with autism spectrum disorders by teaching them appropriate verbal responses (Buggey et al., 1999).

Research is available to support the use of PBS with children with autism in inclusive classrooms (Koegel, Harrower & Koegel, 1999), the home (Clarke, Dunlap, & Vaughn, 1999), and the community (Carr et al., 1999, Carr et al., 1993). Scotti et al. (1996) reviewed current research (30% of the studies included individuals with autism) for adherence to certain standards of practice and noted an increase in the number of studies using nonaversive practices (e.g., skill training, environmental change, reinforcement) and functional assessment strategies. Any concerns regarding PBS appear to revolve around whether the appropriate behavior can be maintained and the time involved with conducting a functional assessment (Carr, Robinson, & Palumbo, 1990). Despite these potential drawbacks, a recent review of the literature (Carr et al., in press) indicates that using PBS is an effective and proactive approach for resolving challenging behaviors in children with autism.

Visual Strategies/Supports

Description of the Approach

Visual supports are things we see that enhance communication such as body language, facial expressions, gestures, and environmental cues (e.g. a calendar, phonebook, or operating instructions). They might utilize objects, pictures, words, or gestures. Visual supports strengthen a child's ability to receive, process, and express information. They may also assist students to better express themselves, but their primary purpose is to increase student understanding (Hodgdon, 1995).

Students with autism frequently are able to better process what they see than what they hear. They may exhibit problem behaviors because they do not understand expectations. Visual supports help to address behaviors that are the result of a lack of understanding, or an inability to communicate effectively (Hodgdon, 1995). Some visual supports that are particularly effective include (Hodgdon, 1995, 1999; Janzen, 1996;):

- Schedules or calendars
- Mini-schedules (that show a short section of a day and requirements)
- Checklists or "to do" lists
- Transition cues (i.e., items that let a child know where he/she is going next; for example, carrying a ball may mean the child is going to P.E.)
- Cue cards that describe expectations and responses in different situations
- Social stories
- Semantic maps, webs, or flowcharts

Efficacy of the Approach

Visual supports are commonly promoted for children with autism. Most studies describe the efficacy of visual supports as they relate to augmentative communication (see previous sections describing the Picture Exchange Communication System, and Augmentative and Alternative Communication). Visual supports have also been used to modify challenging behaviors (see Hodgdon, 1995; Quill, 1995). In one case (Quill, 1995) a preschooler who was nonverbal hummed loudly while chewing food. By using a "hum" picture and a "no hum" picture, he learned not to hum when the cue card was present. Another child engaged in "TV talk" during 70% of her day in the first grade classroom. Previous reinforcement programs using tangibles did not decrease the "TV talk", but the use of a "quiet" and "noisy" card decreased the inappropriate talking to 20% within three months with no tangible reinforcers. Social stories (see previous description in this document) are another form of visual support that can promote positive behaviors.

The literature provides numerous examples regarding the efficacy of visual schedules in helping children understand the events of their day (see Krantz, MacDuff, & McClannahan, 1993; MacDuff, Krantz, & McClannahan, 1993; McClannahan & Krantz, 1999). Visual supports have also been found effective in helping children transition more quickly from one activity to another (Dettmer, Simpson, Smith Myles, & Ganz, 2000).

In their article about intervention for children with autism, Heflin and Simpson (1998) comment that they "consider visual schedules and other supports to be promising methods in need of additional research" (p. 200) so that we know which forms are most appropriate for various groups of children with autism.

PERCEPTIONS OF PARENTS AND PROFESSIONALS REGARDING EFFICACY

Members of the HJR 228 Advisory Panel voiced concerns at their initial meeting regarding the efficacy of the approaches for educating and treating children with autism. Given the divergent views presented by this committee, a component was added to the study's design to determine stakeholder perceptions of the 20 approaches identified by the Advisory Panel.

Parents were requested to rate the effectiveness of the approaches that had been used with their child and professionals were asked to rate the effectiveness of the approaches that had been used with the children with whom they work. While the findings from these data do not provide empirical evidence about the efficacy of the approaches, they do present valid information about the experiences of numerous stakeholders in Virginia.

Perceptions regarding the efficacy of the approaches were obtained from parents, special education teachers, related services personnel, and treatment professionals. Tables 5.1 and 5.2 identify the number of survey respondents from each stakeholder group who reported experience with each approach and the percent of those individuals who found the approach to be effective. Note that the total number of survey participants from each stakeholder group is presented at the top of each table (following the name of the stakeholder group). For each approach, the number of individuals who indicated they had a child or worked with children who received the approach is presented in parentheses next to the percentage of these individuals who found the approach effective. Caution should be exercised in interpreting the findings from these data given the low sample size of some stakeholder groups (e.g., treatment providers) and the lack of data collected about the level of experience each respondent had with the approaches.

Number of Individuals Indicating Experience with the Approaches

An analysis of Table 7.1 reveals that the number of individuals who have experience with specialized approaches varies dramatically depending on the type of approach. Comparisons among stakeholder groups show that parents, special education teachers, and related services personnel most frequently reported experience with PECS, social stories, and sensory integration. For each of these stakeholder groups, these three approaches were one of the top four with the highest number of respondents who indicated they had experience with the approach. In contrast, the approaches with which most treatment providers had experience were play therapy, sensory integration, and applied behavior analysis. Facilitated communication and PECS ranked similarly high. All four stakeholder groups cited the least amount of experience with chelation therapy, SCERTS, and secretin.

The number of individuals in each stakeholder group who had experience with general approaches (see Table 7.2) was substantially more than the number who indicated experience with specialized approaches. Almost all (88% or more) special education teachers and related services personnel indicated that they had experience with positive behavior supports, inclusion, and visual strategies/supports. The majority were also experienced with augmentative communication and intensive early intervention. Well over half of the parents reported experience with inclusion, visual strategies, intensive early intervention, and positive behavior supports. Across stakeholder groups, few individuals reported experience with music therapy. Parents also indicated limited experience with augmentative communication. The experiences of treatment providers (i.e., who serve children outside the school setting) were not obtained.

Table 7.1
Percent of Parents and Professionals Who Used Specialized Approaches and Found Them to Be Effective

Specialized Approach	Parents (N=847)	Special Education Teachers (N=146)	Related Service Providers (N=314)	Treatment Providers (N=55)
Applied Behavior Analysis (ABA)	68% (300)	44.9% (69)	43.4% (189)	62.9% (27)
Auditory Integration Training	38% (195)	34.2% (41)	21.2% (94)	5% (20)
Chelation Therapy	56% (36)	12.5% (8)	12.5% (16)	0% (8)
Facilitated Communication	44% (203)	39.2% (51)	32.5% (154)	15.4% (26)
Floor Time	52% (265)	39.1% (46)	57.7% (110)	45% (20)
Picture Exchange Communication System (PECS)	63% (451)	64.4% (90)	74.4% (240)	68% (25)
Play Therapy	51% (359)	57.1% (49)	61.7% (159)	26.4% (34)
Social Communication Emotional Regulation and Transactional Supports (SCERTS)	46% (48)	33.4% (12)	54.6% (33)	16.7% (6)
Secretin	26% (106)	16.7% (24)	3.4% (58)	0% (11)
Sensory Integration Training	55% (340)	45.8% (72)	53.4% (210)	29.1% (31)
Social Stories	51% (354)	60% (104)	61.5% (234)	4.3% (19)
Special Diet	43% (296)	15.8% (57)	22.7% (168)	4.3% (23)
TEACCH Model/Structured Teaching	56% (305)	65.7% (70)	75.3% (186)	43.4% (23)
Vitamin Therapy	43% (291)	9.1% (33)	12.4% (105)	0% (15)

* The number in parentheses following each percentage indicates the total number of individuals (i.e., the valid N) who reported that they had used the approach.

Table 7.2
Percent of Parents and Professionals Who Used General Approaches and Found Them to Be Effective

General Approach	Parents (N=847)	Special Education Teachers (N=146)	Related Services (N=314)
Augmentative Communication	56% (216)	54.8% (84)	62.8% (231)
Intensive Early Intervention	71% (467)	78.1% (87)	78.9% (242)
Inclusion With Non-Disabled Peers	61% (596)	54.6% (130)	51.8% (284)
Music Therapy	66% (303)	44.8% (58)	60.5% (139)
Positive Behavioral Supports	71% (395)	78.1% (132)	72% (289)
Visual Strategies/Supports	62% (519)	81.2% (128)	82.6% (287)

* The number in parentheses following each percentage indicates the total number of individuals (i.e., the valid N) who reported that they had used the approach.

Effectiveness of the Approaches

Survey respondents found the general approaches to be as effective or more effective than many of the specialized approaches. Across stakeholder groups, there was less variability in the ratings of the general approaches than of the specialized approaches (i.e., the percentage of individuals who found the approach effective varied more with the specialized approaches than the general approaches). Since treatment providers were not given the opportunity to rate the general approaches, it is unclear whether the consistency in ratings would have extended to include this stakeholder group. Interestingly, if one eliminates the non-educational specialized approaches (e.g., chelation therapy, special diet, vitamin therapy) there appears to be greater consistency among stakeholders in their ratings of specialized approaches.

There were numerous differences among stakeholder groups regarding perceptions of the efficacy of the specialized approaches (see Table 5.1). PECS was the only approach where more than 50% of the respondents across all four groups agreed on effectiveness. Over half of the parents, special education teachers, and related services personnel also believed that TEACCH/structured teaching, play therapy, and social stories were effective approaches. While several other specialized approaches were identified as effective by a majority of individuals within one or two stakeholder groups, these perceptions were not shared across other groups. Less than half of the stakeholders within each of the four groups found auditory integration training, facilitated communication, secretin, special diet, and vitamin therapy to be effective. Parents consistently rated these five approaches more effective than all other stakeholder groups.

There was much greater consensus among stakeholder groups regarding the effectiveness of the general approaches (see Table 5.2). With only one exception (i.e., music therapy), over half of the parents, special education teachers, and related services personnel believed that all of the general approaches were effective. Of the specialized and generalized approaches, intensive early intervention and positive behavior supports were rated as effective by the greatest percentage of stakeholders (over 70%). Although visual strategies, TEACCH, and PECS were perceived as equally or more effective by respondents from certain stakeholder groups, early intervention and PBS were the two approaches that generated the strongest agreement across all groups.

Summary

While it is tempting to draw conclusions about the efficacy of the approaches based on these data, it should be remembered that these data represent only stakeholder perceptions. They do not take into account how the approach was implemented for each child, the length of time it was employed, or how personal judgments about effectiveness were derived. In addition, some of the ratings are based on a very small number of respondents who had experience with the approach. Clearly what is supported by these data are the need for multiple approaches and recognition that all approaches do not necessarily work for every child. Each of the 20 approaches was perceived to be effective by at least some of the respondents. Additional research will help to define the circumstances under which children may and may not benefit from a particular approach.

Challenges in Serving Children with Autism Spectrum Disorders

OVERVIEW

Professionals were asked to identify the greatest challenge they face in providing services to children with autism spectrum disorders. Special education teachers, related services personnel, special education administrators, treatment providers, Local Interagency Coordinating Council (LICC) coordinators, and Community Services Board (CSB) mental retardation (MR) directors responded to this question in an open ended written format as part of a survey they completed. Focus groups were also held with three statewide technical assistance (TA) provider groups to address this question.

Although many of the themes that emerged were similar across stakeholder groups, the relative emphasis placed on each theme varied considerably among groups. The overall themes that emerged clustered around the following challenges:

- Lack of information, trained teachers/professionals, services, resources, and time
- Meeting diverse student needs
- Coordination of services and cooperation among professionals
- Lack of knowledge about autism
- Negative attitudes and conflicting expectations
- Obtaining an accurate diagnosis
- Funding streams do not cover autism
- Providing/funding the intensity of services requested
- Determining effective approaches

One interesting observation is that six of the seven groups cited the issue of "lack of information, trained teachers/professionals, services, resources, and time" as the major challenge in meeting the needs of children with autism. The seventh group rated it second. No other theme was consistently identified across all groups in this way.

This chapter provides a brief description of the themes generated by each stakeholder group and concludes with a comparison among the groups, providing a rank order assessment of the importance with which the themes were identified within each group.

FINDINGS

Challenges Identified by Special Education Teachers (N=146)

- Lack of Planning Time, Space, Funds, Materials, and Trained Teachers. Lack of planning time was expressed as a major challenge for special education teachers serving students with autism spectrum disorders. The availability of funds, materials, and space were also referred to as concerns. In addition, respondents indicated that there are insufficient numbers of qualified teachers and other professionals to work with children with autism spectrum disorders, including qualified and willing substitute teachers. The provision of appropriate support for teachers and large caseloads were also cited as challenges.

- Meeting Diverse Student Needs. Meeting the diverse and individualized needs of students with autism spectrum disorders was identified as a major concern among a large number of special education teachers. Teachers discussed the difficulties involved with serving children with a wide range of abilities in one classroom (i.e., children with mild autism to severe autism), addressing the behavioral issues and communication needs of students, and including students with autism in general education classrooms. In addition to these challenges, teachers found it challenging to assess students and determine the appropriate level of services needed.

- The Need for Training. Special education teachers spoke of their lack of understanding about autism. A fair number admitted that they did not have the proper training to serve this population and expressed a need for additional training that addressed the wide range of needs of children with autism spectrum disorders. They also indicated that general education teachers, paraprofessionals, administrators, and parents could benefit from training.

- Negative Attitudes and Conflicting Expectations. Special education teachers rated parent-school tension as one of the challenges they face. Many noted a lack of flexibility among parents and teachers. Tension was also evident among professionals within the school building as evidenced by the low interest level and or resistance among some general education teachers to accept students with autism in their class and the overall lack of general acceptance and tolerance of students with autism in the school building.

- Lack of Coordination and Cooperation Among Team Members. Coordination and follow through with professionals and parents, cooperation among general education and/or special education staff, and lack of communication among team members were cited as challenges by a small number of teachers.

Challenges Identified by Related Services Personnel (N=314)

- Lack of Information, Trained Teachers/Professionals, Services, Resources, and Time. Related services personnel indicated that they lacked a wide range of resources needed to meet the needs of students with autism spectrum disorders. The most frequently cited resource needs were for planning time, professional development, and trained teachers/professionals. Other resource needs included classroom space, information about autism, and teaching materials. Due to a lack of resources, large caseloads were also cited as a challenge.

- Meeting Diverse Student Needs. Serving children across the spectrum (who have very diverse needs) was cited as a major challenge. Related services personnel expressed concern about how the individual needs of these students could be met when they were all served within the same classroom. Related to this concern was what was described as a lack of knowledge about the full spectrum of the disorder. Other challenges associated with the diversity of student needs focused on diagnosis and placement, sensory integration and communication needs, inappropriate placements, behavior issues, and transition from school to adulthood.

- Lack of Coordination of Services and Cooperation Among Professionals. Challenges exist in coordinating services for children. Related services professionals cited concerns about the level of cooperation evidenced between general education and special education staff, the degree to which students with autism were included in both general and special education classes, the coordination of services among teachers and various treatment providers, and the follow-through by staff on student IEP objectives and other educational plans.

- Lack of Knowledge About Autism. Cited as an important challenge in serving students with autism was the lack of knowledge among all stakeholders (e.g., administrators, parents, general and special education teachers, other professionals) regarding autism. A fair number of survey respondents specifically indicated that paraprofessionals were not appropriately trained to work with this population of students.

- Negative Attitudes and Conflicting Expectations. Survey participants indicated a lack of flexibility among parents, teachers, and other professionals as a challenge in serving children with autism spectrum disorders. A number of related services personnel indicated that there is sometimes considerable tension between school personnel and parents. Some believe that this tension can sometimes lead to "burn out" among those serving this population.

Challenges Identified by Special Education Administrators (N=66)

- Lack of Trained Teachers, Funds, Materials and Space. The greatest challenge cited by special education administrators was finding adequate numbers of trained teachers and other professionals. Related to this were concerns over retaining teachers once they were hired. The need for funds, materials, and space were also mentioned as concerns.

- Negative Attitudes and Conflicting Expectations. This theme includes what administrators described as a lack of flexibility among parents and professionals regarding educational approaches, or an unwillingness to try or accept educational approaches other than those in which individuals strongly believed were “best”. Administrators expressed concern about the lack of acceptance and tolerance of children with autism spectrum disorders among some teachers, students, and other individuals. In some cases, tension exists between parents and school professionals.

- Meeting Diverse Student Needs. Administrators cited the challenge of meeting the diverse needs of students with autism. This theme includes the need for access to teaching strategies unique to autism, improved coordination of recommendations made by study team members, and increased cooperation of general education staff in meeting the needs of students in the general education classroom.

- Lack of Knowledge About Autism. There is a great need to educate parents and professionals about autism. The primary challenge exists in providing training that addresses the full spectrum of the disorder and the wide range of student needs.

Challenges Identified by Treatment Providers (N=55)

- Lack of Trained Professionals and Other Resources. Lack of adequate resources was identified as a significant challenge to providing services for children with autism. These resources included trained professionals, services, funds, school and community education programs, information about autism, effective therapies, and appropriate and timely referrals.

- Parent Stress. Treatment providers spoke of a variety of issues they see parents face that create challenges for them. These include lack of insurance coverage, tensions between parents and schools, a lack of effective treatments, difficulty obtaining respite care and community supports, and the isolation of families. Treatment providers also found it challenging to help families advocate for their children and to connect them with needed services.

- The Need for Training and Education. Treatment providers expressed a need for more education and training in the area of autism spectrum disorders, particularly for parents. Training is needed to help others understand autism and the wide range of children's needs.

- Meeting Diverse Student Needs. Treatment providers discussed the challenges inherent in working with children with a wide range of abilities and needs; and the resulting issues associated with creating and implementing effective educational plans, and including children with autism spectrum disorders in general education classrooms.

- Negative Attitudes and Not Yet Proven Theories. Treatment providers voiced concerns about the lack of research-based curriculum and treatments available, expressing apprehension over the use of "unproven and or disproven treatments" with some children. Many have observed a lack of flexibility among some professionals with regards to the treatments they employ.

- Accurate Diagnosis. Difficulty with accurately diagnosing autism was raised as a challenge. This theme is related to the need for training and education but was specific enough to warrant its own category. Some treatment providers were skeptical about the accuracy of some diagnoses and felt that in some cases there is an over identification of the disorder.

Challenges Identified by LICC Coordinators (N=22)

- Lack of Qualified Service Providers. Adequate numbers of qualified service providers are not available to offer early intervention services for young children with autism spectrum disorders. Most LICC coordinators noted difficulty finding providers with expertise in specialized, intensive approaches for educating children with autism.

- Accurate Early Diagnosis. Few professionals are willing or able to diagnose young children (i.e., under age 3) with autism spectrum disorders. Many are not knowledgeable about this population. Some coordinators indicated that they must send children to other areas of the state for diagnosis because professionals in their area refuse to identify young children with a label of autism.

- Providing and Funding the Intensity of Services Requested. Parents and experts are requesting intensive levels of services that LICCs find difficult to provide. The services are costly and it is hard to find personnel to provide the frequency/intensity of services requested. Some coordinators expressed concerns about their ability to offer intensive services in the natural environment.

- Determining Effective Approaches. Differences exist in the field about the effectiveness of the available approaches for serving children with autism spectrum disorders. Lack of agreement in the field regarding "best practices" makes it difficult for some parents to choose appropriate services. Other parents request specific education and treatment approaches without adequate information about the choices available. Conflicting philosophies and lack of knowledge about available approaches make it challenging for parents and LICC staff to determine appropriate services.

Challenges Identified by MR Directors (N=20)

- Funding Streams Do Not Cover Autism. There is currently no state funding to support services for individuals with autism spectrum disorders. In order to receive services, individuals must have an accompanying disability of mental retardation, mental health, or substance abuse. Insufficient funds exist to serve this population. Clarity is needed regarding the locus of responsibility for autism services in Virginia. MR directors were almost unanimous in voicing this challenge.

- Lack of Expertise Among CSB Staff and Service Providers. CSB staff possess expertise in mental retardation, mental health, and substance abuse issues. They are not adequately prepared to address the needs of individuals with autism. Finding qualified service providers with expertise in autism has also been challenging for CSBs that serve children with a dual diagnosis of mental retardation and autism.

Challenges Identified by Technical Assistance (TA) Providers (N=15)

- Lack of Knowledge About Autism. TA providers are often conducting consults and training at a basic level because of the low knowledge level of individuals in the field. TA providers felt that many of the teachers with whom they work did not receive adequate preservice training.

- Lack of Qualified Professionals to Diagnose Autism Spectrum Disorders. Parents are traveling outside the state (e.g., North Carolina, Tennessee, Maryland, DC) to obtain an initial diagnosis for their child. Diagnosis is not happening early enough in Virginia. Pediatricians are telling parents "just wait and see."

- Lack of Cooperation and Coordination. Collaboration among service providers is difficult. Challenges exist in coordinating services among parents, general education teachers, special education teaches, administrators, IEP committee members, and various service providers.

- Providing Technical Assistance Across Large Geographic Areas. TA providers often drive long distances to provide consultations and trainings. This travel time limits the number of contact hours staff have available to provide assistance.

- Misevaluation of Communication Issues. Focus group members articulated that people don't always associate behavior with communication or the curriculum. One focus group member pointed out that "They don't know to ask for help on these issues because they only see the behavior in isolation. The initial call is usually for behavior. When you get there you find the student has no communication system, there's no structure in the classroom, and the teacher knows nothing about sensory issues." It was emphasized that communication is integral to children with autism yet many speech therapists want to stop services by fourth or fifth grade if a student does not possess a functional communication system.

- Lack of Information, Appropriate Services, and Resources. Limited information on autism is made available to parents and professionals. It is difficult to ensure that individuals who are serving children with autism spectrum disorders are informed about appropriate services, resources, and support for families. TA providers also cited a lack of consistency in the quality of services available for children with autism across Virginia. Some areas of the state have very limited access to quality treatment providers and other services.

Group Comparisons

Many of the themes identified were mentioned across several groups. The relative emphasis each group placed on the challenges varied (see Table 8.1). As such, comparisons among the groups should be made cautiously (refer to the detailed themes under each stakeholder group above). For example, within the theme of "Lack of Information, Trained Teachers/Professionals, Services, Resources, and Time", special education teachers emphasized the limits of time while administrators emphasized the availability of trained teachers. One interesting observation is that six of the seven groups cited the preceding theme as the major challenge in meeting the needs of children with autism. The seventh group rated it a close second. Table 8.1 illustrates the order of importance each group placed on the overall themes identified (i.e., a 1 signifies the theme mentioned most frequently by the participants, a 2 signifies the second most frequently mentioned theme).

Table 8.1
Comparisons Among Stakeholder Groups** Regarding
Expressed Challenges in Serving Children with Autism Spectrum Disorders

Theme	Special Education Teachers	Related Services Personnel	Special Education Adm.	Treatment Providers	TA Providers	LICC Coordinators	MR Directors
Lack of Information, Trained Teachers/ Professionals, Services, Resources, and Time	1	1	1	1	1	1	2
Meeting Diverse Student Needs	2	2	3	4	*	*	*
Coordination of Services and Cooperation Among Professionals	5	3	*	*	3	*	*
Lack of Knowledge About Autism	3	4	4	3	2	*	*
Negative Attitudes and Conflicting Expectations	4	5	2	5	*	*	*
Accurate Diagnosis	*	*	*	6	4	2	*
Funding Streams Do Not Cover Autism	*	*	*	*	*	*	1
Providing/Funding the Intensity of Services Requested	*	*	*	*	*	3	*
Determining Effective Approaches	*	*	*	*	*	3	*

*Theme was not identified by this group

Strategies for Improving Services in Virginia

OVERVIEW

Parents and professionals were asked to identify steps that could be taken by the Commonwealth of Virginia to improve services for children with autism spectrum disorders. Special education teachers, related services personnel, special education administrators, treatment providers, Local Interagency Coordinating Council (LICC) coordinators, and Community Services Board (CSB) mental retardation (MR) directors responded to this question in an open ended written format as part of a survey they completed. Focus groups were also held with three statewide technical assistance (TA) provider groups to address this question.

Toward the conclusion of the study, members of the HJR 228 Advisory Panel and Study Group met to review the preliminary recommendations generated across all stakeholder groups. Members of the Advisory Panel and Study Group were divided into four groups. Each group was asked to review the recommendations and rank order the top five recommendations they believed would significantly improve services for children with autism spectrum disorders in Virginia. Once each group reached consensus about the top five recommendations, the four groups reported their findings and justified their selections to the whole group. Based on the ratings, the whole group agreed that the following recommendations, originated from the stakeholders, would make the most significant impact on improving services for children with autism spectrum disorders in Virginia:

- Provide more training for individuals working with children with autism spectrum disorders. This training should promote eclectic, research-based approaches that reflect best practices. Educate parents about the various treatment approaches, services, and resources available.

- Across all disciplines, provide university course work that addresses the needs of children with autism spectrum disorders. Professionals should be adequately prepared to work with this population upon exiting their preservice training program.

- Train treatment providers to accurately diagnose children with autism spectrum disorders. These providers should possess the skills to identify children at a young age so that children can receive appropriate early intervention services.

- Make community services (i.e., those not provided by the school) more available, accessible, and equitable across the state. Disseminate information about these services.

- Require insurance companies to cover services, therapies, and treatments for children with autism spectrum disorders.

Although many of the themes that emerged were similar across stakeholder groups, the relative emphasis placed on each theme varied considerably among groups. This chapter provides a brief description of the themes generated by each stakeholder group.

FINDINGS

Themes From Parents (N=847)

- Provide more training for individuals working with children with autism. Parents identified an array of individuals who could benefit from additional training in autism including general and special education teachers, paraprofessionals, administrators, treatment professionals, and parents. One of the central recommendations regarding training was that it be provided to all individuals who are working with children with autism spectrum disorders and that the training be intensive in nature. University and college programs that prepare professionals to work with individuals with disabilities also need to include specific training related to educating and treating children with autism spectrum disorders.

- Educate parents about treatment approaches, services, and resources. Many parents commented that they were not aware of all of the services and approaches to educating/treating autism until they completed their survey. They emphasized the importance of providing parents with easy to obtain information that would allow them to make informed decisions and understand how to "navigate the system". It was suggested that parents might benefit from a "one-stop@ place to obtain all needed information.

- Educate the public about autism. Many individuals are not knowledgeable about autism except for what they see through the media. Parents recommended that increased efforts be placed on educating the public and increasing their awareness about autism.

- Increase collaboration among parents and school personnel. Some parents provided tremendous amounts of information about the problems they had experienced with obtaining appropriate school services for their child. These experiences had usually occurred over an extended period of time. Many parents felt that their requests had not been adequately heard or considered. Parents indicated they do not want to beg and fight for services. There is a great need to improve working relationships among parents and school professionals.

- Train treatment providers to accurately diagnose children. Parents felt there were not enough qualified professionals available to diagnose children with autism spectrum disorders. Diagnoses are hard to obtain and parents must often consult multiple doctors before obtaining a diagnosis. Treatment providers need to be trained to diagnose children at a young age so that they can benefit from appropriate early intervention services.

- Professionals who diagnose children need to provide parents with follow up information. Once parents obtain a diagnosis they need additional information on how to obtain services. Many parents felt lost after the initial diagnosis and commented that the individuals providing the initial diagnosis were not helpful in informing them of the services available for their child.

- Provide more funding for school and community services. Parents identified a broad array of needs requiring additional funding and resources. There was limited agreement regarding the type of services needed. Parents clearly indicated that the school or community services their child needed could be provided only if more funding were available.

- <u>Schools should increase their expectations for children with autism spectrum disorders</u>. Some parents felt that school personnel did not have high enough expectations for children with autism spectrum disorders. They felt that there needed to be less "babysitting" in the classroom and better instruction.

- <u>Require insurance companies to cover services, therapies, and treatments related to autism</u>. Some parents have insurance that fully covers their child with autism spectrum disorders while others have insurance that excludes services related to the child's disability. Parents expressed frustration with not having adequate insurance to meet their child's needs.

- <u>Services need to be affordable and accessible</u>. The expense of non-school services was cited as a major barrier to parents in obtaining appropriate services for their child. In addition, some indicated that they must travel great distances to obtain services or are not able to obtain the level of services they want due to inadequate numbers of qualified professionals in their area.

- <u>Ensure student placement in schools is based on the student=s individual needs</u>. Some parents wanted to see an increase in special schools, others wanted more inclusion in the general education classroom, and still others wanted less multi-categorical grouping in self-contained classrooms. Taken collectively, the data from parents within this theme support the need for a continuum of placements.

- <u>Increase opportunities for children to learn social/communication skills</u>. Many parents indicated a desire for their child to spend more time with peers. Some desired alternatives to full inclusion. All expressed interest with this (social/communication skills) being the focal point of instruction.

- <u>Increase/maintain paraprofessional support in classrooms</u>. Paraprofessionals have had a positive impact on the educational progress of children with autism. For many parents, having additional paraprofessional support staff in the classroom meant that their child would receive the supports he/she needed.

Themes From
Special Education Teachers (N=79)

- <u>Individuals who work with children with autism spectrum disorders should be adequately trained</u>. The most important theme that emerged from special education teachers was the recommendation that all individuals who work with children with autism spectrum disorders should receive more training. They indicated that the training should be more in-depth, less general, and include more specialized approaches. Some also advocated that it be provided locally during work hours. Although the vast majority of respondents focused on the need for increased inservice training, a few emphasized the need for training on autism at the preservice level and/or the development of a specific teacher license in the area of autism.

- Provide more funding and resources. Increased funding and resources were recommended to hire more staff, provide additional services, hire consultants, cover the costs of teacher preparation, provide staff development, and increase teacher compensation.

- Make services more available, accessible, and equitable across the state. Disseminate information about available services. Many teachers noted a need for more services and assistance for parents of children with autism. They indicated that some parents have difficulty obtaining services because their child does not have a label of "mental retardation" and hence does not qualify for services outside the school setting. Teachers also indicated that increased coordination among service providers and improved collaboration between home and school would improve existing services for children with autism spectrum disorders.

- Limit class sizes. Provide more staff. Many special education teachers indicated that classrooms for children with autism spectrum disorders are too large and that they have too many children on their caseloads to adequately meet the needs of each child. They believe the situation could be improved by hiring more staff and limiting class sizes.

- Ensure that student placement and special education services and supports are individualized to meet the needs of each child. Student placement was of great concern to many special education teachers. Their recommendations regarding placement varied across opposite ends of the continuum. On one end, teachers felt that students with autism should be placed in classrooms according to their ability level, rather than grouped in an "autism classroom" with students who have very diverse skills. On the other end, teachers recommended placing all children with a label of autism in an "autism classroom", believing that this placement would allow teachers to meet their specialized needs.

- Promote eclectic, research-based approaches that reflect best practices. Disseminate information about effective practices. Special education teachers voiced concern about the lack of curriculum guidance available for teaching children with autism spectrum disorders. Many recommended disseminating guidelines to teachers about best practices and effective inclusion strategies. A few recommended the development of a statewide curriculum for children with autism while others advocated the use of multiple approaches for meeting diverse student needs.

Themes From
Related Services Personnel (N=242)

- Individuals who work with children with autism spectrum disorders should be adequately trained. The predominant theme that emerged from related services personnel is the need for increased preservice and inservice training that focuses on the needs of children with autism spectrum disorders. The primary recommendation within this theme is to provide more training to all service providers and parents, and to increase awareness of autism among the general public. A second recommendation is to train treatment providers to accurately diagnose children at an early age. Respondents indicated that there is both under and over identification of children with autism. Identifying children earlier (instead of giving them a label of "developmentally delayed") would help children to receive appropriate early intervention services. A third recommendation is to provide college coursework that addresses the needs of children with autism spectrum disorders. Most favored embedding information about autism in all professional study programs. Few indicated a need for a separate teacher endorsement in autism.

- <u>Ensure that student placement and special education services and supports are individualized to meet the needs of each child</u>. Within this theme, there are four inter-related recommendations. First, a variety of placement options should be available. There was support for both an inclusive service delivery system (i.e., serving children in general education classrooms) and placement in self-contained special education classrooms. Many suggested that children should be grouped by ability level when they are in special education classrooms, citing that often these children do not receive the specialized instruction they need when they are grouped with children with other types of disabilities. Second, more teachers, paraprofessionals, and specialists are needed to optimally educate children with autism spectrum disorders. Staffing patterns should reflect the needs of the student. Third, caseloads for related services personnel need to decrease as do class sizes for children with autism spectrum disorders. A lower teacher-student ratio would have a positive impact on student learning. Finally guidelines are needed regarding instructional programming for children with autism spectrum disorders. Limited knowledge exists regarding what constitutes an effective education program for these children.

- <u>Provide more funding and resources.</u> There was great variety in the expressed needs for funding and resources. Some of the needs included assistive technology, classroom space, instructional materials, resource libraries, better compensation for staff, appropriate equipment, paid professional development, and hiring consultants. Only one of the requests was for a non-school related expense (i.e., money for parents to purchase services not covered by their insurance). Many recommended making funding and resources for schools more equitable across the state.

- <u>Make community services more available, accessible, and equitable. Widely disseminate information about available services and how to navigate " the system" to obtain services.</u> Related services personnel advocated for more community services including respite care, in-home support, day care, supported employment, vocational assessment and training, residential options (e.g., group homes, apartments), Medicaid Waiver services, services from the Community Services Boards, and recreation opportunities. Services are especially needed in rural areas and should be available for all children who require these supports. In addition, there needs to be a concerted effort to disseminate information to parents, school personnel, and treatment providers about the services available in Virginia. A coordinated system for accessing these services is needed.

- <u>Increase collaboration among parents and professionals. Provide adequate support to teachers and increase their access to specialists with expertise in autism.</u> Many indicated a need for increased coordination and collaboration among parents and service providers (especially school personnel). There needs to be an emphasis on a team approach that is built on trusting relationships, open communication, and consensus building. Related services personnel also believe that teachers need to receive increased support, including more time for planning and collaborating with parents and other team members, regular access to an autism specialist, qualified mentors for new or provisionally licensed teachers, and release time to attend on-going professional development outside the school.

- Promote eclectic, research-based approaches that reflect best practices. Disseminate information about effective practices. Respondents spoke at great length about the need to promote a variety of approaches for working with children with autism spectrum disorders. Often they felt that only one approach was advocated (i.e., by parents, treatment providers, school systems) and that one approach was not necessarily effective with all children. Information about the effectiveness of the various approaches (as defined by research-based studies) needs to be made available to parents and service providers so that informed decisions can be made about education and treatment options.

Themes From
Special Education Administrators (N=53)

- Individuals who work with children with autism spectrum disorders should be adequately trained. The strongest recommendation offered by special education administrators was that more training be available for school personnel and parents. In general, these respondents advocated that the training be more intensive than typical conferences and require "hands-on" experiences. Also important was that training be offered regionally and that funds be available to support the training. A third of the respondents supporting this theme recommended that information about autism be included in the preservice training received by school personnel (especially by general and special educators). A small minority favored the development of a separate teacher endorsement in autism.

- Provide more funding and resources. Requests for additional funds for serving children with autism spectrum disorders were diverse in nature. Many administrators did not specify how they would use additional funds if they received them. Those needs that were expressed included hiring autism specialists and additional support staff, professional development, assistive technology, incentives to attract prospective educators, and applied behavior analysis.

- Promote eclectic, research-based approaches that reflect best practices. Disseminate information about effective practices. Administrators emphasized the need for school personnel to be trained to implement a variety of research-based approaches. Educational approaches should be selected for each child based on the child's individual needs. One approach should not be singled out as the only approach for all children. Information on approaches that constitute best practice need to be clearly communicated across the state through inservice training and written guidelines.

- Make services more available, accessible, and equitable across the state. Administrators identified "services" as both school services and community services. Many wanted to increase existing services or have access to a wider array of services in their locality. Some of the services needed included access to instruction in the student's home school (i.e., the school the student would attend if they did not have a disability), alternative placements, residential supports (e.g., group homes, apartments), branches of VARC and TAP, more staff, and assistance attracting qualified teachers.

Themes From
Treatment Providers (N=39)

- Individuals who work with children with autism spectrum disorders should be adequately trained. Treatment providers identified an array of professionals (special and general education teachers, paraprofessionals, physicians, other health care providers, clinical professionals) who need to receive training on autism as part of their standard university preparation. Training should focus on effective, research-based approaches. More service providers within each discipline need to be trained to work with children with autism spectrum disorders. In addition, information about autism should be disseminated to families as well as the community at large. There needs to be a better way of providing training and disseminating information in rural areas.

- Make services more available, accessible, and equitable across the state. Disseminate information about available services. Increased publicity about the services available for children with autism spectrum disorders would help parents to understand their options. Some suggested that this could be done by disseminating a coordinated set of information regarding state and local services through the Autism Society of America chapters or through physicians. Services that were cited as needing to be more available, accessible, and equitable included diagnostic evaluations, early intervention, reimbursement for services through insurance companies, and respite care.

- Increase coordination among service providers. Schools and agencies that provide services for children with autism spectrum disorders could reduce duplication of services by coordinating resources. There is a need for educational and medical personnel to work together more effectively. Methods for increasing coordination include developing a statewide DD (developmental disabilities) service delivery system and identifying common points of coordination within each geographic region of the state.

Themes From
LICC Coordinators (N=20)

- Individuals who work with children with autism spectrum disorders should be adequately trained. More training is needed for all individuals serving children birth to age three with autism spectrum disorders. Physicians need to be educated about the benefits of early diagnosis and early intervention. More providers need to be trained to work with this population and the public needs to be made aware of what it means to have autism.

- Make services more available, accessible, and equitable across the state. All children need to receive consistent levels of services based on their needs. Adequate amounts of services need to be provided based on recommended, research-based practices. Rather than services being provided based on need (i.e., children need to be poor in order to qualify for free services), some coordinators recommended that services be provided more equitably across children. Services should be less costly to parents and there should be greater consistency among insurance companies regarding the services they cover. Individuals living in rural areas identified a need for greater accessibility to services.

- Provide more funding and resources. LICC coordinators identified a diverse array of funding needs. The most frequent recommendations for funding were in the areas of early intervention services and staff development. Other individual recommendations suggested increased funding for hiring staff, public awareness, diagnosis, and services from statewide technical assistance providers (i.e., TAP and VARC).

- Disseminate information about effective practices. Parents and professionals need more guidance about effective strategies for educating and treating autism spectrum disorders. Information should be disseminated about research-based approaches so that teams supporting children can make informed decisions.

Themes From
MR Directors (N=18)

- Provide more funding, resources, and services. Almost all of the MR directors recommended increased funding for children with autism spectrum disorders. They indicated that a funding source for autism is needed within CSBs and Virginia's disability services system in order for services to be provided to this population. Funds are specifically needed to increase services through the Medicaid Waiver program, provide additional services that go beyond the Medicaid Waiver program, and provide incentives to attract and maintain service providers.

- Offer more training and public awareness about autism. About half of the MR directors suggested that service providers need additional training to enhance their skills in working with individuals with autism. Efforts need to focus on expanding the number of qualified service providers to work with this population. In addition, attention should be given to increasing the public's awareness of autism.

Themes From
TA Providers (N=15)

- Individuals who work with children with autism spectrum disorders should be adequately trained. Among all TA providers the need for education and training was one of the most emphasized recommendations for improving services for children with autism. Training will help to increase acceptance of the disability. Some people think about children with autism as individuals with a severe disability but they are not aware of how it affects children at the opposite end of the spectrum. Focus group members stressed that people need to learn to have higher expectations for children with autism. Universities also need to do a better job of preparing future educators and treatment professionals to work with children with autism. Practicing professionals need to receive on-going staff development to maintain and increase their skills.

- Develop a better system to coordinate disability services in Virginia. There is a need for a new and/or better system to coordinate services across the state. Participants suggested that the current system is a "hodge podge" approach that is inefficient and should be disbanded because its services are too narrow. Many participants felt that services could be better coordinated by developing a DD (developmental disabilities) system which could serve a broader array of individuals with disabilities. Also emphasized was the need for consistency of services across the state. The same services need to be available in all localities. Currently, each school division defines its own services, thus preventing families from accessing the same services from all areas of the state. Participants emphasized the need for statewide leadership in the area of autism.

- Increase coordination among service providers. This theme consists of three inter-related parts. First, TA providers indicated that there is a need for a new and/or better system to coordinate services across the state. Participants suggested that the current system is a "hodge podge" approach that is inefficient and should be disbanded because its services are too narrow. The system could be improved by broadening it to become a DD (developmental disabilities) system. Second, participants emphasized the need for consistency in services across the state. The same services need to be available in all localities. Currently, each school division defines their own services, thus preventing families from accessing the same services from all areas of the state. Third, all service providers need to come together across the state to coordinate their efforts and avoid duplication of services. A statewide interdisciplinary task force should be developed to address lifespan issues for persons with autism in Virginia. This group could be responsible for updating the HJR 228 study report annually and tracking the data across time.

- Increase collaboration among parents and professionals. There is a need for increased trust between schools and families. Schools frequently become defensive and cannot imagine how parents could know more than the professionals. One way to build trust would be to involve parents and school personnel in joint training activities.

- Provide more funding, resources, and services. Focus group participants emphasized the need for increased funding for services for children with autism. More money is need for schools to use for communication equipment, instructional materials, and professional development. Funding is also needed to support statewide programming from birth through adulthood (not just early intervention). More support and direct services should be provided for families.

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APPENDIX A

HOUSE JOINT RESOLUTION NO. 228

Offered January 24, 2000

Requesting the Departments of Education, Health, and Mental Health, Mental Retardation and Substance Abuse Services to study the services available for children with autism and pervasive developmental disorders.

Patrons-- Thomas, Clement, Hall, Hamilton, Plum, Robinson, Van Landingham and Woodrum

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Referred to Committee on Rules

WHEREAS, a study conducted in California indicates that the population of children with autism or pervasive developmental disorders may be growing; and

WHEREAS, several different types and levels of autism are recognized, including autistic disorder, pervasive developmental disorder, NOS (not otherwise specified), Asperger's disorder, Rett's disorder, and childhood disintegrative disorder; and

WHEREAS, the parents of young children with these disorders have expressed concerns about the lack of services and expertise on autism and pervasive developmental disorders in various areas of the Commonwealth; and

WHEREAS, many of these parents are struggling to find help and feel that there is inadequate guidance, particularly in some more rural areas of Virginia; and

WHEREAS, young parents need a systematic approach or sense of direction in the treatment and education of their young autistic children; and

WHEREAS, these disorders are complex conditions that are still the subject of debate regarding the proper diagnostic techniques, the actual diagnoses, and the best approaches to treatment, training, and education; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Departments of Education, Health, and Mental Health, Mental Retardation and Substance Abuse Services be requested to study the services available for children with autism and pervasive developmental disorders. The Department of Education shall serve as lead agency on this study. The Departments shall examine the characteristics, number, and location of children with autism and pervasive developmental disorders in Virginia; availability of teachers and other special education and treatment professionals; the level of expertise found in the various areas of Virginia; and the adequacy of the available services for children with autism and pervasive developmental disorders. The Departments shall also evaluate the various treatment and education approaches and make recommendations concerning the efficacy of these approaches and ways to increase services to the children and their parents. Technical assistance may be provided to the Departments by the school divisions of Virginia.

All agencies of the Commonwealth shall provide assistance to the Departments for this study, upon request. The Departments may seek the assistance of physicians, psychologists, and other experts in the relevant disorders.

The Departments of Education, Health, and Mental Health, Mental Retardation and Substance Abuse Services shall complete their work in time to submit their findings and recommendations to the Governor and the 2001 Session of the General Assembly as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents.

APPENDIX B
HJR 228 Advisory Panel

Susan Anderson
Developmental Pediatrician
Kluge Children's Rehabilitation Center
Charlottesville

Georgia Brown
Speech Language Pathologist
SECEP, Virginia Beach

Suzanne Butcher
Parent
Vice President, Autism Society of America,
Northern Virginia Chapter

Mary Cole
Director of Mental Retardation Services
Cumberland Mountain CSB

Charlotte Crane
Autism Resource Specialist
Loudoun County Public Schools

Leslie Daniel
Severe Disabilities Coordinator
T/TAC at Virginia Tech

Rosanna Hartmann
Parent
President, Autism Society of America,
Greater Roanoke Valley Chapter

Bradford Hulcher
Parent
Information and Referral Specialist
Autism Society of America,
Central Virginia Chapter
Glen Allen

Allison Coles Johnson
Parent
Advisory Board Member, TAP and VBPD
Richmond

Marty Lenehan
Parent
Lynchburg

Al Klugh
Special Education Teacher
Chatham Elementary School

Jane Kroboth
Parent
Acting Director, The Autism Program
of Virginia
Richmond

Donald Oswald
Associate Professor, Department of Psychiatry
Virginia Commonwealth University
Richmond

Shamsi Sadeghzadeh
Senior Consultant
Virginia Autism Resource Center
Winchester

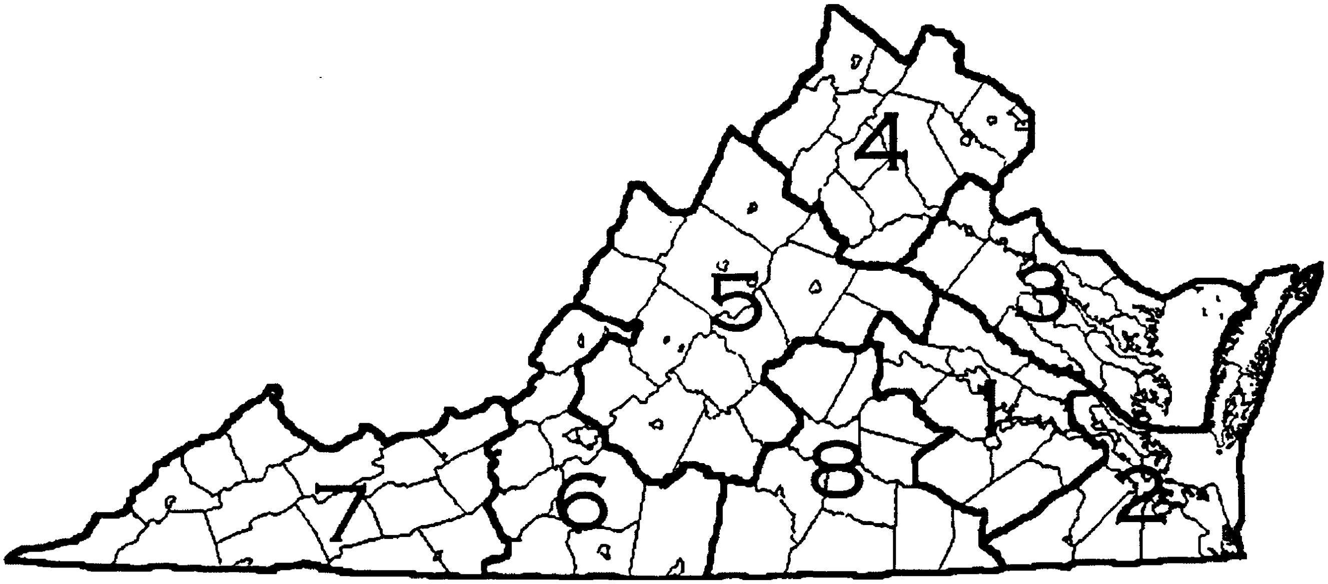
Beth Sarrett
Instructional Specialist
Chesterfield County Schools

Thomas Saucedo
Parent
Autism Society of America,
Northern Virginia Chapter

Susan Shaw
Council Coordinator
Blue Ridge Infant and Toddler Council
Charlottesville

Joan Spratley
Director of Special Education
Norfolk City Schools

APPENDIX C - SUPERINTENDENT'S REGIONS



Region 1
Charles City
Chesterfield
Colonial Heights*
Dinwiddie
Goochland
Hanover
Henrico
Hopewell*
New Kent
Petersburg*
Powhatan
Prince George
Richmond*
Surry
Sussex

Region 2
Accomack
Chesapeake*
Franklin*
Hampton*
Isle of Wight
James City
Newport News*
Norfolk*
Northampton
Portsmouth*
Southampton
Suffolk*
Virginia Beach*
Williamsburg*
York

Region 3
Caroline
Colonial Beach*
Essex
Fredericksburg*
Gloucester
King George
King & Queen
King William
Lancaster
Mathews
Middlesex
Northumberland
Poquoson*
Richmond
Spotsylvania
Stafford
West Point*
Westmoreland

Region 4
Arlington
Clarke
Culpeper
Fairfax
Fauquier
Frederick
Loudoun
Madison
Manassas*
Manassas Park*
Orange
Page
Prince William
Rappahannock
Shenandoah
Warren

Region 5
Albemarle
Amherst
Appomattox
Augusta
Bath
Bedford
Botetourt
Campbell
Charlottesville*
Fluvanna
Greene
Harrisonburg*
Highland
Lexington*
Louisa
Nelson
Rockbridge
Rockingham
Staunton*
Waynesboro*

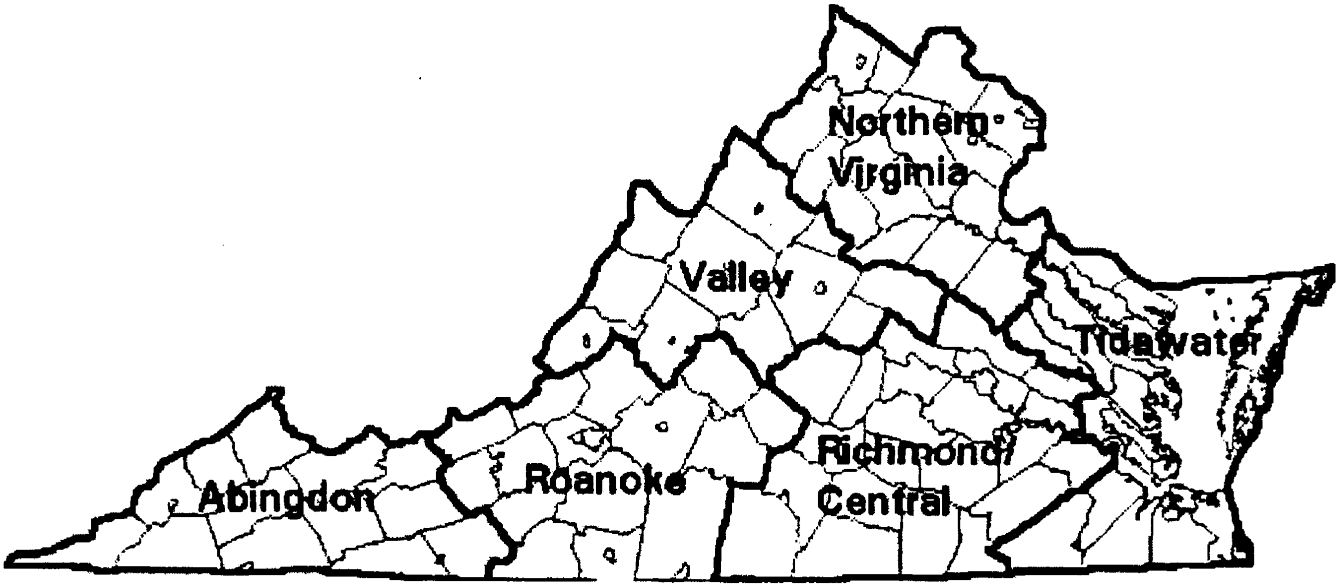
Region 6
Allegheny
Botetourt
Covington*
Craig
Danville*
Floyd
Franklin
Henry
Martinsville*
Montgomery
Patrick
Pittsylvania
Roanoke
Roanoke*
Salem*

Region 7
Bland
Bristol*
Buchanan
Carroll
Dickenson
Galax*
Giles
Grayson
Lee
Norton*
Pulaski
Radford*
Russell
Scott
Smyth
Tazewell
Washington
Wise
Wythe

Region 8
Amelia
Brunswick
Buckingham
Charlotte
Cumberland
Greensville
Halifax
Lunenburg
Mecklenburg
Nottoway
Prince Edward

*denotes independent city/town

APPENDIX D - LOCAL INTERAGENCY COORDINATING COUNCIL REGIONS



Abingdon

- Abingdon*
- Bland
- Bristol*
- Buchanan
- Carroll
- Dickenson
- Falls Mills*
- Galax*
- Grayson
- Lee
- Marion*
- Norton*
- Russell
- Scott
- Smyth
- Tazewell
- Washington
- Wise
- Wythe

Roanoke

- Amherst
- Appomattox
- Bedford
- Bedford*
- Botetourt
- Campbell
- Craig
- Danville*
- Floyd
- Franklin
- Giles
- Henry
- Lynchburg*
- Martinsville*
- Montgomery
- Patrick
- Pittsylvania
- Pulaski
- Radford*
- Roanoke
- Roanoke*
- Salem*

Valley

- Albemarle
- Allegheny
- Augusta
- Bath
- Buena Vista*
- Charlottesville*
- Clifton Forge*
- Covington*
- Fisherville*
- Fluvanna
- Greene
- Harrisonburg*
- Highland
- Lexington*
- Louisa
- Nelson
- Rockbridge
- Rockingham
- Staunton*
- Waynesboro*

North. Virginia

- Alexandria*
- Arlington
- Caroline
- Clark
- Culpepper
- Fairfax
- Fairfax*
- Falls Church*
- Fauquier
- Frederick
- Fredericksburg*
- King George
- Loudoun
- Madison
- Manassas*
- Manassas Park *
- Orange
- Page
- Prince William
- Quantico*
- Rappahannock
- Shenandoah
- Spotsylvania
- Springfield*
- Stafford
- Warren
- Winchester*

Richmond/Cent.

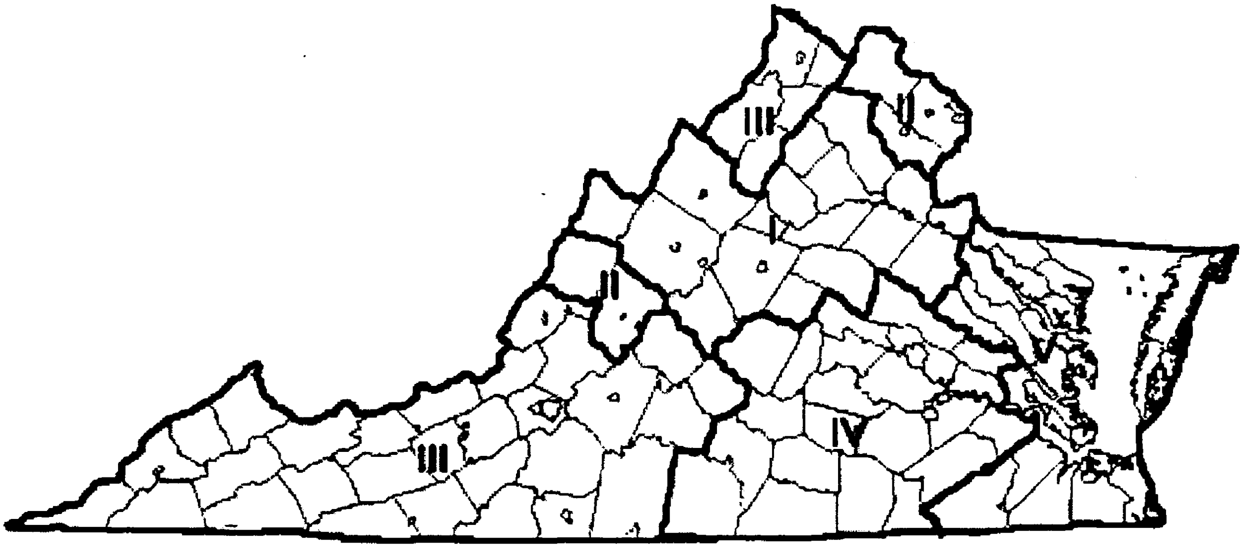
- Amelia
- Brunswick
- Buckingham
- Charles City
- Charlotte
- Chesterfield
- Colonial Heights*
- Cumberland
- Dinwiddie
- Emporia*
- Goochland
- Greensville
- Halifax
- Hanover
- Henrico
- Hopewell*
- Lunenburg
- Mecklenburg
- New Kent
- Nottoway
- Petersburg*
- Powhatan
- Prince Edward
- Prince George
- Richmond*
- South Boston*
- South Hill*
- Surry
- Sussex

Tidewater

- Accomack
- Chesapeake*
- Colonial Beach*
- Essex
- Franklin*
- Gloucester
- Hampton*
- Isle of Wight
- James City
- King & Queen
- King William
- Lancaster
- Mathews
- Middlesex
- Newport News*
- Norfolk*
- Northampton
- Northumberland
- Poquoson*
- Portsmouth*
- Richmond
- Southampton
- Suffolk*
- Virginia Beach*
- West Point*
- Westmoreland
- Williamsburg*
- York

* denotes independent city/town

APPENDIX E – VIRGINIA COMMUNITY SERVICES BOARDS



Region I
Albemarle
Augusta
Caroline
Charlottesville*
Culpeper
Fauquier
Fluvanna
Fredericksburg*
Greene
Harrisonburg*
Highland
King George
Louisa
Madison
Nelson
Orange
Rappahannock
Rockingham
Spotsylvania
Stafford
Staunton*
Waynesboro*

Region II
Alexandria*
Arlington
Bath
Buena Vista*
Fairfax
Fairfax*
Falls Church*
Lexington*
Loudoun
Manassas*
Manassas Park*
Prince William
Rockbridge

Region III
Alleghany
Amherst
Appomattox
Bedford
Bedford*
Bland
Botetourt
Bristol*
Buchanan
Campbell
Carroll
Clarke
Clifton Forge*
Covington*
Craig
Danville*
Dickenson
Floyd
Franklin
Frederick
Galax*
Giles
Grayson
Henry
Lee
Lynchburg*
Martinsville*
Montgomery
Norton*
Page
Patrick
Pittsylvania
Pulaski
Radford*
Roanoke
Roanoke*
Russell
Salem*
Scott
Shenandoah
Smyth
Tazewell
Warren
Washington
Winchester*
Wise
Wythe

Region IV
Amelia
Brunswick
Buckingham
Charles City
Charlotte
Chesterfield
Colonial Heights*
Cumberland
Dinwiddie
Emporia*
Goochland
Greensville
Halifax
Hanover
Henrico
Hopewell*
Lunenburg
Mecklenburg
New Kent
Nottoway
Petersburg*
Powhatan
Prince Edward
Prince George
Richmond*
Surry
Sussex

Region V
Accomack
Chesapeake*
Essex
Franklin*
Gloucester
Hampton*
Isle of Wight
James City
King & Queen
King William
Lancaster
Mathews
Middlesex
Newport News*
Norfolk*
Northampton
Northumberland
Poquoson*
Portsmouth*
Richmond
Southampton
Suffok*
Virginia Beach*
Westmoreland
Williamsburg*
York

*denotes independent city/town