

**REPORT OF THE  
JOINT COMMISSION ON HEALTH CARE**

**Needs of Individuals with  
Autism Spectrum Disorder  
Who Are Transitioning from  
Secondary Schools  
(SJR 330 – 2013)**

**TO THE GOVERNOR AND  
THE GENERAL ASSEMBLY OF VIRGINIA**



**SENATE DOCUMENT NO. 4**

**COMMONWEALTH OF VIRGINIA  
RICHMOND  
2014**

**Code of Virginia § 30-168.**

The Joint Commission on Health Care (the Commission) is established in the legislative branch of state government. The purpose of the Commission is to study, report and make recommendations on all areas of health care provision, regulation, insurance, liability, licensing, and delivery of services. In so doing, the Commission shall endeavor to ensure that the Commonwealth as provider, financier, and regulator adopts the most cost-effective and efficacious means of delivery of health care services so that the greatest number of Virginians receive quality health care. Further, the Commission shall encourage the development of uniform policies and services to ensure the availability of quality, affordable and accessible health services and provide a forum for continuing the review and study of programs and services.

The Commission may make recommendations and coordinate the proposals and recommendations of all commissions and agencies as to legislation affecting the provision and delivery of health care.

For the purposes of this chapter, "health care" shall include behavioral health care.

## **Joint Commission on Health Care Membership**

### **Chair**

**The Honorable Linda T. Puller**

### **Vice-Chair**

**The Honorable John M. O'Bannon, III**

### **Senate of Virginia**

The Honorable George L. Barker  
The Honorable Harry B. Blevins  
The Honorable Charles W. Carrico, Sr.  
The Honorable L. Louise Lucas  
The Honorable Stephen H. Martin  
The Honorable Jeffrey L. McWaters  
The Honorable Ralph S. Northam

### **Virginia House of Delegates**

The Honorable Robert H. Brink  
The Honorable David L. Bulova  
The Honorable Benjamin L. Cline  
The Honorable Rosalyn R. Dance  
The Honorable T. Scott Garrett  
The Honorable Algie T. Howell, Jr.  
The Honorable Riley E. Ingram  
The Honorable Christopher K. Peace  
The Honorable Christopher P. Stolle

The Honorable William A. Hazel, Jr.  
Secretary of Health and Human Resources

---

### **Commission Staff**

Kim Snead  
Executive Director

Stephen W. Bowman  
Senior Staff Attorney/Methodologist

Michele L. Chesser, PhD  
Senior Health Policy Analyst

Jaime H. Hoyle  
Senior Staff Attorney/Health Policy Analyst

Sylvia A. Reid  
Publication/Operations Manager

## **Preface**

The associated symptoms of autism spectrum disorder (ASD) affect multiple areas of an individual's life across his/her lifetime, including education/training, employment, housing, and health care. Studies have shown that better interventions and supports across the lifespan can help persons with ASD live more independently.

The Individuals with Disabilities Education Act guarantees services for persons with ASD through age 21 if they are eligible for special education services. After age 21, persons with ASD must seek out services and meet various eligibility requirements. Planning for this transition begins at age 14 in Virginia. Families, ASD advocates, and State representatives report the success of transition planning varies depending on the geographic location of the individual, the school division, and the institutional knowledge of persons included on the transition team.

The primary sources of services and support for adults with ASD include Medicaid waivers for community-based services and the employment assistance provided through the Department for Aging and Rehabilitative Services (DARS). With enrollment caps and waiting lists, Medicaid waivers currently do not provide the necessary support for all adults in need; furthermore, case management services are only available for adults who receive waivers or DARS-supported services. Improvements in providing access to affordable and accessible housing are being undertaken by the Department of Behavioral Health and Developmental Services through waiver reform and implementation of the settlement agreement with the United States Department of Justice.

Eight policy options were presented for consideration by members of the Joint Commission on Health Care, who voted to take no action.

Joint Commission members and staff would like to acknowledge and thank those who assisted in this study including numerous individuals with ASD and their families and representatives from the Charlottesville Region Autism Action Group, Commonwealth Autism Services, Department for Aging and Rehabilitative Services, Department of Behavioral Health and Developmental Services, Department of Education, Department of Medical Assistance Services, Faison School, Joint Legislative Audit and Review Commission, Project SEARCH, Virginia Association of Community Services Boards, Virginia Board for Persons with Disabilities, and Virginia Commonwealth University Autism Center for Excellence.



# Table of Contents

BACKGROUND.....1

TRANSITION SERVICES.....2

STUDY FINDINGS .....4

POLICY OPTIONS AND PUBLIC COMMENT ...10

## ATTACHMENTS:

SEPTEMBER 17, 2013 PRESENTATION TO THE  
JOINT COMMISSION ON HEALTH CARE

SENATE JOINT RESOLUTION 330 (2013)



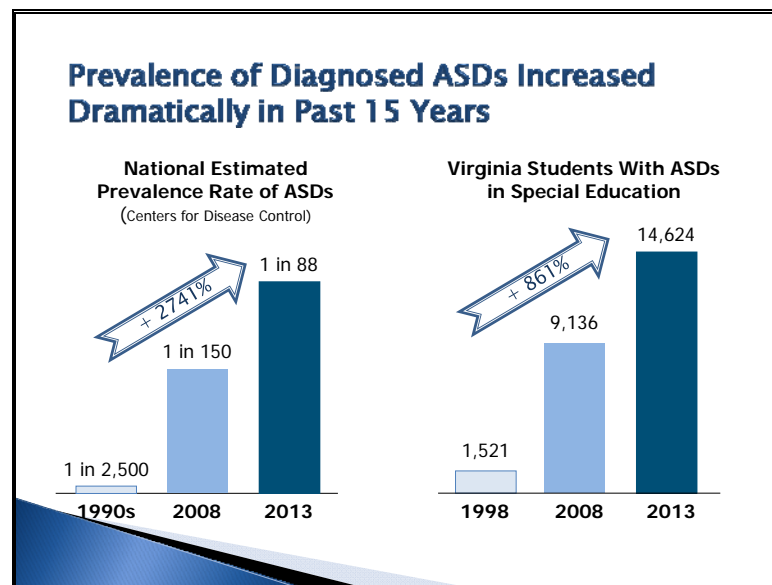
## Needs of Individuals with ASD Transitioning from Secondary Schools

Senate Joint Resolution 330, introduced by Senator Ralph S. Northam in 2013, directed the Joint Commission on Health Care (JCHC) to study the needs (including needs related to housing, employment, and day support services) of individuals with autism spectrum disorder transitioning from public and private secondary schools.

### Background

The Centers for Disease Control and Prevention (CDC) define autism spectrum disorders (ASDs) as “a group of developmental disabilities that can cause significant social, communication and behavioral challenges....[Being a spectrum disorder] means ASD affects each person in different ways, and can range from very mild to severe.”<sup>1</sup> ASD usually appears in early childhood and the associated impairments may affect multiple areas of an individual’s life throughout his/her lifespan although symptoms may improve over time. The primary service needs of a person with ASD include health care, education/training, employment, and housing. Studies have shown early intervention with an emphasis on social development may improve symptoms of ASD, and better interventions and supports across the lifespan can help persons with ASD with varying needs live more independently.

According to a 2012 CDC report, an estimated 1 in 88 children have an ASD. In March 2013, the CDC released the results of a parent survey which suggest the prevalence rate to actually be 1 in 50. The prevalence rate of ASD has continued to increase significantly in Virginia also, as shown in the following figure.



Source: Nathalie Molliet-Ribet, Senior Associate Director, JLARC presentation to the Autism Advisory Council in 2013.

<sup>1</sup> <http://www.cdc.gov/ncbddd/autism/facts.html>

While there is no cure for ASD, early intervention and treatment can have a significantly positive impact on the lives of persons with ASD. Related medical expenses are often costly; the CDC found on average annual medical expenditures were \$4,110 to \$6,200 higher for individuals with ASD than for individuals without an ASD.<sup>2</sup> In Virginia, the average medical cost in 2005 for Medicaid-enrolled children with an ASD was \$10,709 per child as compared with the average cost of \$1,812 for children without an ASD. In addition to medical costs, intensive behavioral interventions for children with ASD typically cost \$40,000 to \$60,000 per child/per year. A 2006 study by the Harvard School of Public Health found the average lifetime cost to care for a person with ASD to be \$3.2 million.

## **Transition Services**

The federal Individuals with Disabilities Education Act (IDEA)<sup>3</sup> requires public schools to provide all students who require special education services, including those with ASD, a free and appropriate public education to meet their unique needs and prepare them for further education, employment, and independent living. The IDEA mandates special education and related services for children ages two through 21 who have a disability that negatively impacts their access to the general curriculum with transition planning which must begin by age 16.

In Virginia, students with disabilities who have individualized education plans (IEPs) begin developing a transition plan at the age of 14. According to IDEA, transition planning needs to be outcome-oriented, based on the student's strengths and areas of need, and focused on instruction and services for education, employment, and other independent living skills. The purpose of transition planning is to ensure that children are provided opportunities to develop needed skills while they are still covered under IDEA. Under IDEA, the transition team should include:

- The student (as appropriate)
- The student's parents or guardians
- Teachers (special and general education)
- School administrators
- Related service providers such as speech therapists, behavioral consultants, etc.
- Representatives of outside agencies that may provide support to reach post-transition goals
- Other individuals who can support the student.

IDEA guarantees services for persons with ASD through age 21 if he/she is eligible for special education. However, as individuals with ASD transition into adulthood, they move from an entitlement system into an eligibility system. IDEA funding and services are no longer available once a student has received a high school diploma or aged out of the school system. At that point, the individual must seek out services and meet various eligibility requirements. Many individuals and their family members reported they were not prepared for this transition and felt left on their own to navigate a complex system of funding, supports, and agencies.

Currently, the primary sources of services for adults with ASD are Medicaid waivers for community-based services, employment supports provided by the Department for Aging and Rehabilitative Services (DARS), and related case management services. With capped

---

<sup>2</sup> <http://www.cdc.gov/ncbddd/autism/data.html>

<sup>3</sup> Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004).



## Funding and Programs for Individuals with ASD (birth – 21)

Age	Program	Department/Office
0–5	Child Development Clinics	Department of Health
	Early Intervention Part C	Dept. of Behavioral Health and Developmental Services
	School Part B (2–5)	Department of Education
	Comprehensive Services Act	Office of Comprehensive Services
	Intellectual Disabilities Waiver	Department of Medical Assistance Services
	Day Support Waiver	Dept. of Behavioral Health and Developmental Services
	Elderly Disabled Consumer Directed Waiver	Department of Medical Assistance Services
6–21	Child Development Clinics	Department of Health
	Early Intervention Part C	Dept. of Behavioral Health and Developmental Services
	School Part B	Department of Education
	Comprehensive Services Act	Office of Comprehensive Services
	Intellectual Disabilities Waiver	Department of Medical Assistance Services
	Day Support Waiver	Dept. of Behavioral Health and Developmental Services
	Elderly Disabled Consumer Directed Waiver	Department of Medical Assistance Services
16–21	Vocational Rehabilitation	Department for Aging and Rehabilitative Services
	Woodrow Wilson Rehabilitation Center	Department for Aging and Rehabilitative Services
	Centers for Independent Living	Department for Aging and Rehabilitative Services

enrollments and waiting lists, Medicaid waivers currently fail to guarantee access to services for all adults in need. Additionally, only the most severely disabled meet functional needs eligibility. With regard to case management, these services are only available for adults enrolled in Medicaid waivers or DARS programs and are limited in availability; furthermore, not all case managers are trained regarding the specific needs of individuals with ASD.

Five of the seven Medicaid waivers serve individuals with ASD, including:

- Day Support Waiver for Individuals with Intellectual Disability (Day Support Waiver)<sup>4</sup>
- Elderly or Disabled with Consumer-Direction Waiver (EDCD Waiver)<sup>5</sup>
- Individual and Family Development Disabilities Supports Waiver (DD Waiver)<sup>6</sup>
- Intellectual Disability Waiver (ID Waiver)<sup>7</sup>
- Technology Assisted Waiver (Tech Waiver)<sup>8</sup>

<sup>4</sup> The Day Support waiver only serves persons who are on the statewide waiting list for the ID Waiver; CSBs provide case management services.

<sup>5</sup> The EDCD waiver serves eligible elderly individuals and adults and children with disabilities and a medical need. There is no waiting list for this waiver.

<sup>6</sup> The DD waiver serves eligible adults and children aged 6 or older who have a developmental disability but no diagnosis of intellectual disability. The DD-waiver waiting list is maintained on a statewide/chronological basis.

<sup>7</sup> The ID waiver serves eligible adults and children with an intellectual disability; a waiting list for waiver services is maintained. The day-to-day ID waiver operations are administered by the Department of Behavioral Health and Developmental Services. At the local CSB-level, a case manager coordinates the ID waiver services.

<sup>8</sup> The Tech waiver serves eligible adults and children “who are chronically ill or severely impaired, needing both a medical device to compensate for the loss of a vital body function and require substantial and ongoing skilled nursing care” providing “a choice of home and community based care services rather than reside in an acute care hospital, long stay hospital or specialized care nursing home.” There is no waiting list for this waiver. (Department of Medical Assistance Services website – [http://dmasva.dmas.virginia.gov/Content\\_pgs/ltc-wvr\\_ta.aspx](http://dmasva.dmas.virginia.gov/Content_pgs/ltc-wvr_ta.aspx))

Funding and Programs for Adults (22+) with ASD	
Program	Department
Medicaid Waivers	
Intellectual Disabilities	Dept. of Behavioral Health and Developmental Services
Day Support	Dept. of Behavioral Health and Developmental Services
Individual & Family Developmental Disabilities	Department of Medical Assistance Services
Elderly Disabled Community Directed	Department of Medical Assistance Services
Rehabilitation Programs	
Vocational Rehabilitation	Department for Aging and Rehabilitative Services
Woodrow Wilson Rehab Center	Department for Aging and Rehabilitative Services
Centers for Independent Living	Department for Aging and Rehabilitative Services

*Virginia's Settlement Agreement with U.S. Department of Justice Requires More Integrated Community-Based System of Care.* An investigation, initiated by the Department of Justice in 2008, began with a review of the Central Virginia Training Center and was subsequently expanded to incorporate “Virginia’s compliance with the Americans with Disabilities Act (ADA) and *Olmstead*...[and] the statewide system serving individuals with intellectual and developmental disabilities.”<sup>9</sup> The 10-year settlement agreement reached between the Commonwealth of Virginia and the U.S. Department of Justice in 2012 requires significant changes in the provision of community-based care for individuals with developmental disabilities (including individuals with ASD). These planned changes, which generally are not reflected in this report, include adding waiver slots and increasing the focus on employment of individuals with intellectual and developmental disabilities.

## Study Findings

While this report generally reflects the current state of service-provision for individuals with ASD, the study findings may be useful in moving toward a more integrated community-based system of care.

### TRANSITION PLANNING AND CASE MANAGEMENT FINDINGS

**Finding 1: Families reported difficulty in navigating the system of services, programs, and funding for children and adults with ASD, despite the provision of mandated transition services.**

Moving from an entitlement system with guaranteed services and funds, to an eligibility system with limited services and funding options often comes as a surprise to individuals and families. Families reported being overwhelmed with the choices they needed to make in order to prepare for a future with limited support choices and available funding. They reported missing opportunities because they felt unsupported and ill-equipped to navigate a complex system with multiple agencies, support services, and funding sources.

Effective transition planning is especially important for students with ASD: Research indicates young adults with ASD are less likely to have ever lived independently after high school than

<sup>9</sup> Department of Behavioral Health and Developmental Services, *U. S. Department of Justice Implementation Update*, RD 171 (2012), p. iii.

adults with other disabilities<sup>10</sup> and have worse employment outcomes in the first few years after high school than do peers who have other types of disabilities.<sup>11</sup>

**Finding 2: Successful transition requires more consistent collaboration between schools, DOE, DARS, and community services boards (CSBs) to ensure adults with ASD identify and access available community resources.**

The 2009 JLARC Report, *Assessment of Services for Virginians with Autism Spectrum Disorder*, found “transition planning and services may not address the unique needs of students with ASD.” In that report, JLARC recommended the Virginia Department of Education (DOE) develop transition guidelines, create transition specialist positions, and expand vocational and life skills training. In response to the JLARC recommendations, DOE issued guidelines for transition planning which include:

- Characteristics of excellent transition programs
- Transition team composition
- Transition assessment
- Educational and transition planning
- Instruction for transition age youth in natural environments
- Addressing challenging behavior through positive behavior supports
- Navigating adult services
- Postsecondary education
- Workplace challenges and supports
- Home living skills
- Recreation and leisure skills
- Social Security and benefits planning

DOE requires schools to assign a case manager to each person with an IEP, and in larger school districts, they require transition coordinators as well. These coordinators match students with ASD with community resources and act as liaisons between community services agencies and students, their families, and the case managers.

In order to allow schools considerable flexibility in meeting the varying needs of individuals with ASD, the DOE transition standards are guidelines rather than policy. Consequently, successful transition planning is often dependent on where the student lives, in what school district he/she resides, and the expertise and institutional knowledge of the persons on the transition team.

Ideally the transition team would consistently include a representative from DARS, and all schools would have collaborative agreements in place with their local DARS field offices. In practice, there is no consistent referral process which would allow DARS to anticipate and plan for individuals with ASD reaching transition age. In fact, most local schools rely on the student’s family to invite representatives from other agencies, such as DARS or CSBs, to the transition meetings. Families are not the experts regarding available community resources and should not be responsible for determining which agency representatives should be at initial transition

---

<sup>10</sup> Anderson, Kristy A., Shattuck, Paul T., Cooper, Benjamin P., Roux, Anne M., Wagner, Mary. “Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder.” *Autism*, August 30, 2013. Online.

<sup>11</sup> Roux, Anne M., Shattuck, Paul T., Cooper, Benjamin P., Anderson, Kristy A., Wagner, Mary, Narendorf, Sarah C. “Postsecondary Employment Experiences Among Young Adults with an Autism Spectrum Disorder.” *Journal of the American Academy of Child & Adolescent Psychiatry*. 52.9: 931-939. (2013).

meetings. A number of families reported that collaboration between DOE, DARS, and CSBs during transition planning occurred inconsistently; thereby, failing to ensure students with ASD learn about and access available community resources as they transition into adulthood.

**Finding 3: The lack of consistently available case management services in Virginia hinders successful transition planning.**

One goal, for having the Department of Behavioral Health and Developmental Services (DBHDS) serve as the lead agency for ASD, was to enhance collaboration and coordination and to identify and address service gaps. The finding, noted in the 2009 JLARC report, that “case management services are not consistently available to coordinate the care of Virginians with ASD” continues to be a concern. Adults with ASD must be enrolled in a Medicaid waiver or DARS program to be eligible to receive case management services. While CSBs could take the lead in providing case management for adults with ASD, currently there are not enough CSB-staff trained in addressing the specific needs of individuals with ASD.

**POST-SECONDARY EDUCATION AND EMPLOYMENT**

As noted previously, adults with ASD typically have less favorable employment outcomes and are less likely to have lived independently after high school than adults with other disabilities.<sup>12</sup>

**Finding 4: Transition planning needs to focus on self-determination for individuals with ASD who are interested in completing post-secondary education.**

DOE has created diplomas that will better equip a person with any level of ASD to transition to higher education, a vocation, or meaningful employment including:

- An advanced diploma which is required to attend most four-year colleges and universities.
- A standard diploma which is generally required to attend community colleges.
- A modified diploma which serves certain students “who have a disability and are unlikely to meet the credit requirements for a Standard Diploma.”<sup>13</sup>
- A special diploma that indicates the student has left school with a certain skill-set.

**Virginia ASD Transition Indicators – Awarded Diplomas**

	2010	2011	2012
<b>Advanced</b>	51	54	51
<b>Standard</b>	99	106	148
<b>Modified</b>	23	22	35
<b>Special</b>	73	121	97

Transition planning is very important for students with ASD who are interested in post-secondary education. College students with ASD may qualify for federal funding assistance until they turn 22 years old. Once enrolled in a college or community college, these students need to be self-advocates and seek out any needed support as offered by the disability office of the college campus. For example, although students with Asperger’s syndrome sometimes excel academically, their grades may suffer due to such symptoms as having trouble managing time,

<sup>12</sup> Anderson, Kristy A., Shattuck, Paul T., Cooper, Benjamin P., Roux, Anne M., Wagner, Mary. “Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder.” *Autism*. August 30, 2013. Online.

<sup>13</sup> “The Modified Standard Diploma will not be an option for students with disabilities who enter the ninth grade for the first time beginning in 2012-2014. Credit accommodations allow students with disabilities who previously would have pursued a Modified Standard Diploma to earn a Standard Diploma.” Department of Education announcement at [http://www.doe.virginia.gov/instruction/graduation/modified\\_standard.shtml](http://www.doe.virginia.gov/instruction/graduation/modified_standard.shtml).

communicating and interacting socially, and asking for help. Because persons, who have Asperger's Syndrome or are otherwise high functioning, typically do well academically, their need for ongoing support is often overlooked. Having the self-determination skills to access support from a disability office can make the difference in success or failure for many of these students.

**Finding 5: With appropriate planning and appropriate levels of support across the lifespan, many individuals with ASD are able to find and maintain employment.**

Employment provides the income to allow a person to live independently, but persons with ASD are employed at much lower rates than those with other disabilities; the Southwest Autism Research and Resource Center recently found that the unemployment rate for young adults with ASD is about 90 percent nationally. Employment supports and innovative programs in Virginia have assisted a number of individuals with ASD in finding and maintaining meaningful employment.

*Employment Programs Administered by the Department for Aging and Rehabilitative Services.* DARS provides services to assist individuals with disabilities, including those with ASD, in finding and maintaining meaningful employment. Following the release of the JLARC report in 2009, DARS increased its focus on vocational services to individuals transitioning from high school; increasing the number of individuals receiving employment services from 737 in 2008 to 1,029 in 2010. In fact, 88 percent of those served in 2010 were transition-age youth who often have higher support needs and require more extensive vocational rehabilitation services than other individuals with disabilities served by DARS. The Woodrow Wilson Rehabilitation Center and the Post-Secondary Education Rehabilitation Transition Program are examples of DARS programs that address vocational and social skills needs of individuals with disabilities, including those with ASD in transition.<sup>14</sup>

DARS offers supported employment services, which include the federally-defined program of supported employment and Job Coach Training Services. Supported employment is defined as “competitive work in integrated work settings or employment in integrated work settings in which individuals are working toward competitive work, consistent with the strengths, resources,

---

<sup>14</sup> The Woodrow Wilson Rehabilitation Center provides integrated medical and vocational rehabilitation services addressing the comprehensive needs of clients to improve independence and employability. The campus houses a vocational school and medical rehabilitation units. The Life Skills Training Program has been expanded to meet the needs of more individuals with ASD. After the nine week program, individuals with ASD report significant improvement in social skills. Additionally, the percentage of persons who complete the program and become successfully employed has grown twenty percent.

The Post-Secondary Education Rehabilitation Transition Program (PERT) provides special education high school students, 16 and older, a comprehensive evaluation in the areas of vocational skills, independent living skills, and leisure and social skills. PERT's continuum of short term services includes Exploration Evaluation, Counseling, Work Adjustment Training, Job Placement and Job Maintenance, and Independent Living Skills. These services focus on identifying appropriate choices for secondary students in their local communities. They develop teams (special education, vocational education, rehabilitation counselor, and PERT) to focus on transition needs of students and participating school divisions. The program features vocational assessment and exploration which utilizes hands on situational assessment and integrates vocationally relevant academic assessments. It also offers technical assistance in meeting the specialized needs of students and communities through team field visits and training opportunities. They also have implementation meetings in the community utilizing summary reports which identify appropriate training for the student while he/she is still in high school.

priorities, concerns, abilities, capabilities, interests, and informed choice of the individuals, for individuals with the most significant disabilities....”<sup>15</sup>

If long term supports are necessary, supported employment is often considered; four models of supported employment are currently in use in Virginia:

- The Individual Placement Model in which an “employment specialist places one person at a job site, provides support, and then gradually reduces time and assistance at the work site.”
- The Enclave Model places a small group of supported employees “at a job site in the community where they work together or are dispersed within an integrated setting.” An employment specialist functioning as a full-time enclave supervisor provides ongoing support services.
- The Mobile Work Crew Model employs a small group of supported employees who “travel together to one or more integrated work settings in the community where they perform contract work such as custodial, grounds-keeping and similar functions.” A full-time supervisor provides ongoing support services.
- The Entrepreneurial Model consists of a small group of supported employees who produce “goods or services either on a sub-contract basis or as a prime manufacturer. The individuals in the group, along with the managers and other employees actually comprise the business. Support services are provided by managers and other employees without disabilities who are employed by the business. Supported employees interact with the general public or other employees.”<sup>16</sup>

If long term supports are not required, DARS typically considers Job Coach Training Services, which provides the consumer with an initial situational assessment, job development, job skills training, transportation training, or other support services provided by a private employment services organization. With Job Coach Training Services, extended services are not available and once the employee is stable, DARS will have no more involvement.<sup>17</sup>

DARS’ Long-Term Employment Support Services program provides supported employment services beyond the 90 days allowed by the previously-described supported employment programs. This DARS program, which is funded exclusively with State general fund dollars, assists individuals with ASD who need ongoing support to remain successfully employed with services being provided through contracts with private employment services organizations. Because funding for the program is capped, and in fact has been reduced significantly over the last few years, the program has been unable to serve all of the individuals who require long-term supports. The availability of these employment supports has been reduced due to funding cuts and waiting lists are maintained according to disability categories. The lack of employment supports remains a consistent complaint from individuals with ASD and their families.

***The Employment First Initiative Undertaken by DBHDS.*** DBHDS addresses the lack of employment for persons with disabilities, including those with ASD, through its Employment First initiative. DBHDS adopted an Employment First policy as part of Virginia’s settlement agreement with the Department of Justice. Under the agreement, Virginia must provide integrated day activities and significantly shift the number of individuals in day support programs to integrated day opportunities, including supported employment. Virginia must also work to reach out to business communities in order to educate and increase awareness of

---

<sup>15</sup> DARS Guide to Supported Employment and Job Coach Training Services, p. 4 at <http://www.vadars.org/essp/downloads/SEGuide/SEGuide11.pdf>

<sup>16</sup> DARS Guide to Supported Employment and Job Coach Training Services, pp. 5-7.

<sup>17</sup> DARS Guide to Supported Employment and Job Coach Training Services, pp. 7-8.

employing persons with disabilities. Finally, Virginia must revise Medicaid regulations for the Day Support Waiver to increase flexibility and emphasis on employment as the priority focus.

***The Project SEARCH Program.*** Project SEARCH is a nationally recognized high school transition model, originating at Cincinnati Children’s Hospital Medical Center in 1996. It provides education and employment training for youth with intellectual disabilities, and is dedicated to workforce development that benefits the individual, community and workplace. It currently has more than 140 sites in 42 states with both private and public employers.<sup>18</sup>

Virginia has worked with local business, State service agencies and local public school systems to create and sustain Project SEARCH sites throughout the Commonwealth. The Bon Secours Health System sponsors a Project Search program which is the only program in the U.S. designed specifically for students with ASD. High school seniors aged 18 to 22 apply to the program and are placed in three departments at the hospital during the school year. Each student spends two hours in the classroom for every five hours at their internship.

In 2013, 90 high school seniors in Virginia completed Project SEARCH internships within 11 hospitals and businesses, and all of the students were offered part-time employment.

## **HOUSING**

### **Finding 6: Successful transitioning to independent living requires affordable and accessible housing, which continues to be inadequate in Virginia.**

The range of needs for those on the ASD spectrum requires a range of housing options and individualized living plans. Currently suitable housing options are limited and expensive; the funding for and affordability of housing and related services remain major concerns. Current housing options include: living at home, supported apartment living, group homes, supported independent living, home sharing, and sponsored placement.

The current diagnosis-based waiver system acts as a barrier to persons with ASD finding housing. In order to become eligible for supported housing, one must have an intellectual disability diagnosis since the developmental disability waiver does not cover housing costs or congregate living. This puts disability communities at odds with each other over limited housing options. Through waiver reform as required by Virginia’s settlement agreement with the Department of Justice, DBHDS will address this inconsistency and seek to improve housing options for individuals with ASD. Specifically, DBHDS will move to a waiver system that will be based on level of function and need rather than diagnosis. In addition, changes in reimbursement rates will be recommended in order to serve those with the most complex needs, 4,170 targeted waiver slots will be established by June 2021, and case management capacity within CSBs will be expanded.

The settlement agreement requires DBHDS to serve individuals in the most integrated setting consistent with their informed choice and needs, to assemble baseline information regarding the number of individuals who would choose independent living options, and to develop a plan to increase access to independent living options. As part of the performance contract with CSBs, case managers will be expected on at least an annual basis to explore less restrictive community options to any individual living outside their own home or their family’s home. Finally, the

---

<sup>18</sup>“Averill, Judy. Howlett, Judith. McDonough, Jennifer T., Wittig, Katherine M. “Project SEARCH improves employment outcomes.” Available at <http://www.ttacnews.vcu.edu/2011/01/project-search-improves-employment-outcomes-1/>.

settlement agreement requires that DBHDS examine the waiver to identify barriers to independent living and implement an \$800,000 rental assistance pilot.<sup>19</sup>

### Policy Options and Public Comment

Eight policy options were presented for consideration and comments were submitted by families with children with ASD, Dr. Carol Schall, Commonwealth Autism Services (CAS), the Department of Behavioral Health and Developmental Services, and the Virginia Association of Independent Specialized Education Facilities.

Policy Options		Support	Oppose/ Concern
1	Take no action.	0	0
2	By letter of the JCHC Chair, encourage the Department of Behavioral Health and Developmental Services to publicize its role as lead agency for services for individuals with ASD and to highlight the link to Commonwealth Autism Services as a valuable resource on ASD information, including information related to transition services.	5 The Hagens; Susan Jacobson & M. Oliver; Anonymous family; CAS; VAISES	0
3	Introduce a budget amendment in the amount of \$2.6 million GFs per year to expand vocational rehabilitation services (including case management services) provided by the Department for Aging and Rehabilitative Services in order to address the increasing demand for ASD services and to enable more consistent involvement in transition planning.	5 The Hagens; Susan Jacobson & M. Oliver; Anonymous family; CAS; VAISES	0
4	Introduce a budget amendment in the amount of \$3.4 million GFs and \$600,000 NGFs per year for the Department of Behavioral Health and Developmental Services to allow community services boards to be involved with transition planning and provide case management services for adults with ASD (after the Department of Education is no longer involved).	5 The Hagens; Susan Jacobson & M. Oliver; Anonymous family; CAS; VAISES	0
5	By letter of the JCHC Chair, request the Department of Behavioral Health and Developmental Services work to improve collaboration between its agency, the Department for Aging and Rehabilitative Services, and community services boards for ASD-related services for adults (beginning with transition planning).	5 The Hagens; Susan Jacobson & M. Oliver; Anonymous family; CAS; VAISES	DBHDS
6	By letter of the JCHC Chair, request the Department of Behavioral Health and Developmental Services form a stakeholder workgroup to develop CSB-staff competencies for providing case management for adults with ASD.	5 The Hagens; Susan Jacobson & M. Oliver; Anonymous family; CAS; VAISES	DBHDS
7	Introduce a budget amendment of \$506,000 to \$1,000,000 GFs per year to expand Long-Term Employment Support Services administered by the Department for Aging and Rehabilitative Services.	5 The Hagens; Susan Jacobson & M. Oliver; Anonymous family; CAS; VAISES	0
8	By letter of the JCHC Chair, request that the Joint Legislative Audit and Review Commission conduct a follow-up to its 2009 report on ASD and consider our findings in completing the study.	5 The Hagens; Susan Jacobson & M. Oliver; Anonymous family; CAS; VAISES	DBHDS

<sup>19</sup> "DOJ Housing Plan Update," presented by Eric Leabough, Housing Specialist, Virginia Department of Behavioral Health and Developmental Services. Available at [https://www.dbhds.virginia.gov/settlement/DOJ%20Housing%20Update-Pres\\_1\\_3\\_12.pdf](https://www.dbhds.virginia.gov/settlement/DOJ%20Housing%20Update-Pres_1_3_12.pdf).



## **PUBLIC COMMENT EXCERPTS**

**Commonwealth Autism Services** commented: “The report makes clear the many challenges being faced by individuals with an ASD and their families. In many localities the current system suffers from **poor coordination** among lead organizations (schools, DARS and CSBs), is **inconsistent** (better in some locales than others) **fragmented** (certain components in place with others missing) and significantly **underfunded** (given the numbers of individuals to be served). The report addresses these deficits in its policy options and CAS supports Options 2-8 as a solid starting point for improving the system.

Related to these options are two other current initiatives under way, i.e. waiver reform and the Autism Advisory Council of the General Assembly. CAS supports the creation of a single disability waiver (see attached position statement for specifics) that will enhance serve access post age 22 for young people with an ASD. Additionally, CAS supports the role of the Autism Advisory Council as an accountability mechanism for the 2009 JLARC autism study recommendations. This coupled with an updating of the JLARC study incorporating the JCHC study in its remit will serve as an up to date road map for both public and private organizations involved in the system of care.”

**The Department of Behavioral Health and Developmental Services** provided wording suggestions that were included in this final written report as well as the following comments addressing specific policy options.

With regard to **Option 5**, “Agencies at the state level currently do collaborate successfully on many fronts. We would recommend that this option be re-worded to emphasize the need for strengthening the collaboration that already exists to result in targeted outcomes related to transition planning for individuals with ASD.”

Regarding **Option 6**, “Currently the Virginia Autism Council (VAC) (whose membership includes autism specialist from DOE, DARS, DBHDS, DMAS, VCU, JMU, Lynchburg College, Center for Independent Living – Fredericksburg, Partnership for People with Disabilities, the Board for People with Disabilities, Blue Ridge Autism Achievement Center, Virginia Institute of Autism, Commonwealth Autism Service, The Arc, Autism Society of America Central Virginia Chapter, Didlake Inc. and a self advocate) is in the process of finishing the creation of “Skill Competencies for Professionals and Direct Care Staff for Adults with Autism Across the Life Span.” This should fulfill the intent of a stakeholder workgroup.”

In addressing **Option 8**, “Many changes are currently taking place in the developmental disability service delivery system. The operational management of the DD Waiver is transferring from DMAS to DBHDS in November and a system wide study of the waivers and waiver reimbursement rates is currently underway. It would seem appropriate for any follow-up review of the 2009 JLARC report to be on hold until the changes that are currently underway can be completed.”

## **Peter and Emily Mazure**

Our son “must live with his parents until we are gone. I don't know what will happen to him after that because under the present Waiver situation housing is not an option for a person with the Autism diagnosis. Will he be on street? These are some of Virginia's most vulnerable citizens. We need your help in protecting them. And, we need it soon.”

## **Kristen Davis**

“I agree that the transition process and the way it is handled are extremely important. It has been my experience (as the mother of a 26 year old son with an ASD) that transition planning as part

of the IEP process is really more of a rubber stamp process than anything of real substance or help to the student and/or the families. The results of your study and the experiences of friends whose children have recently "completed" the process (up to and including last year) certainly suggest that this is still the case -- at least in some parts of Virginia. Many families don't know that they can request collaboration between the school and DARS. Your finding that there needs to be collaboration between the DOE, DARS and (I hope CSBs get involved in the process and delivery of services!) CSBs is right on target, and long overdue.

I would like to also comment on the need for housing. I believe this is a major concern that many families are too overwhelmed to address, especially during the transition process. They are too busy trying to navigate a whole new world (mostly on their own or with the help of other parents) after structured lives based around school and IEPs to even begin thinking about something that seems so far down the road. By the time many parents (like me) are ready to tackle housing (and the almost fruitless search for it without the help of a Medicaid Waiver -- and currently the DD Waiver does not provide funds for housing), it is almost too late. I am working with other parents, trying to find or create housing solutions for our adult children with ASD. It is a very challenging undertaking, particularly in Northern Virginia. My goal of finding my son a suitable living situation by the time he turns 30 is starting to feel less and less attainable, and a little more desperate as each day passes.

Finally, I would like to say that I found your study to be thoughtful and thorough. The recommendations throughout are spot on. The only thing that I feel is missing from the study (and SJR 330) is acknowledgement of the needs of young adults who have already gone through their secondary school's transition process, but are still not fully integrated into their communities. Many are unemployed, still live at home, and depend on their parents for many aspects of daily living, including transportation. I believe that anyone with an ASD who has not actually completed the move from the support and structure of secondary school to optimum independence as a member of their own community is still in "transition."

**Mr. and Mrs. Dunn**

"I love this state very much, but I am not sure that it will ever step up and make available the needed resources to serve citizens with disabilities. At present the state is ranked 47<sup>th</sup> in the nation for services to the disabled. I already know at least one family who has left because of this lack of services. Please change this untenable situation:

- Get the Medicaid Waivers moving.
- Properly compensate Medicaid respite workers, so that we can hire safe, reliable and competent caregivers.
- Adequately staff DARS and other service agencies.
- Improve the coordination of services.
- Develop a continuum of housing and post-secondary education services responsive to the extremely wide range of needs and abilities represented in the autism community."

**Dr. Carol Schall, VCU School of Education, Rehabilitation Research and Training Center**  
(based on her experiences with Project SEARCH)

"Given our experience supporting young adults with ASD at work and our research outcomes, we respectfully offer the following recommendations for Virginia to consider:

- There is a need for funds that would support youth with ASD and other similar disabilities who require high intensity initial and long-term supports beyond the current funding rates provided by milestones and Long Term Employment Support Services (LTESS) available. Individuals with ASD are similar to those with traumatic brain injury in that they typically required increased supports to acquire job skills, achieve, and maintain stability in employment settings.
- There is a need for increased training and higher skill sets for DARS Rehabilitation Counselors and Employment Support Staff who provide direct services to youth and adults with ASD.
- There is a need for caseload reduction for professionals providing services to youth with ASD. As we have discovered, this is a specialized population that requires additional time and support above and beyond that of a typical employment services general case load.
- There is a need for more comprehensive community based services for youth with ASD. Many of our clients with ASD experience challenges related to their life experiences outside of work and this may result in complications at work.
- There is a need for increased access to positive behavior supports services for employees with ASD to support their employers in maintaining a successful employment experience.”

***Subsequent Action by the Joint Commission on Health Care.*** During the Joint Commission’s 2013 Decision Matrix meeting, JCHC members voted to take no action.

**JCHC Staff for this Report**

Jaime H. Hoyle  
Senior Staff Attorney/Health Policy Analyst



# Attachments





## **Behavioral Health Care Subcommittee**

### **Needs of Individuals with Autism Spectrum Disorder Who Are Transitioning from Secondary Schools - *Revised* SJR 330– Senator Northam**

**September 17, 2013**

**Jaime Hoyle**  
Senior Staff Attorney/Health Policy Analyst

## **Study Mandate**

- ▶ Senate Joint Resolution 330 (Senator Northam - 2013) directs JCHC to:
  - study the service needs of individuals with autism and autism spectrum disorders transitioning from public and private secondary schools, including needs related to housing, employment, and day support services.

## Agenda

- ▶ Background
  - Prevalence of ASD
  - Funding Streams and Program Availability
- ▶ Transition Planning
  - Legal Requirements
  - Coordination and collaboration
  - Case Management
- ▶ Future Needs
  - Higher Education/Employment
  - Housing
  - Support Services
- ▶ Policy Options

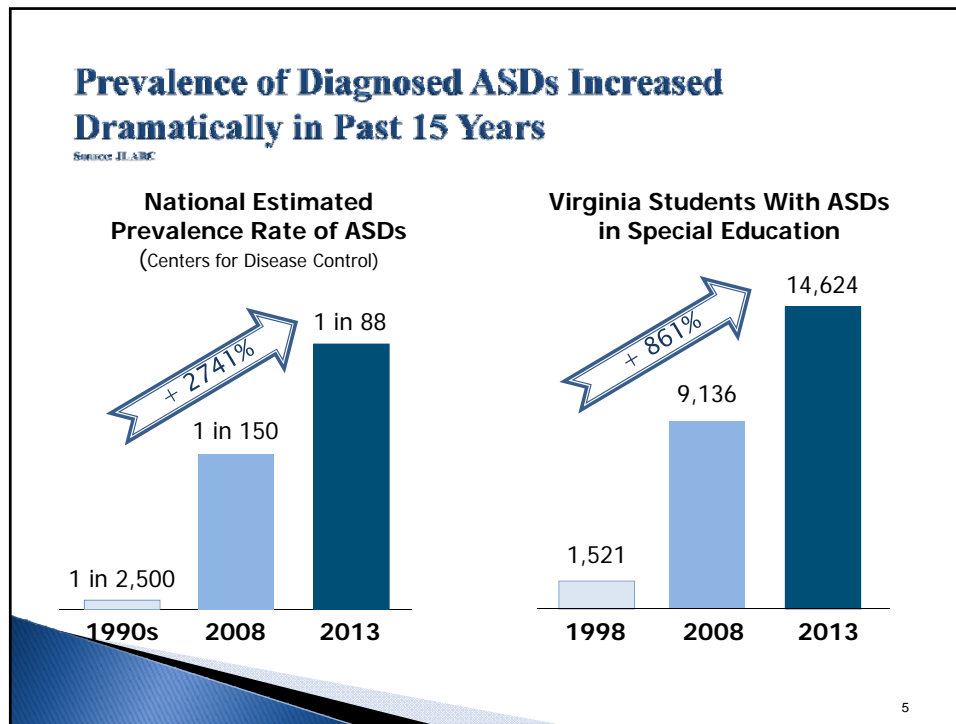
3

## Background

- ▶ Autism Spectrum Disorders (ASDs) are a group of developmental disabilities.
- ▶ ASDs are characterized by atypical development in socialization and behavior, with associated impairments affecting multiple areas of an individual's life.
  - There are many levels of functionality along the spectrum.
- ▶ The primary needs of a person with ASD are education/training, employment, housing, and health care.
  - These needs will remain at some level throughout an individual's lifespan.

4





### Prevalence of ASD in VA

▶ Children with Autism in Virginia:

Age	1999-2000	2010-2011
3-5	228	936
6-11	1,308	6,015
12-17	560	4,010
18-21	132	697
6-21	2,000	10,722
3-21	2,228	11,658

6

## Prevalence of ASD in VA

	2006-2007	2008-2009	2010-2011	2012-2013
PK	370	524	550	761
K	413	635	706	768
1	517	731	989	1,042
2	593	745	1,168	1,334
3	626	828	1,107	1,328
4	563	806	1,038	1,321
5	526	739	984	1,248
6	499	676	916	1,191
7	473	576	823	1,064
8	440	568	769	1,021
9	413	536	660	941
10	354	485	622	799
11	337	471	605	718
12	300	500	766	1,088
Total	6,424	8,820	11,703	14,624

7

## Costs Associated with ASD

- ▶ The CDC also reports that individuals with an ASD had average medical expenditures that exceeded those without an ASD by \$4,110–\$6,200 per year.
- ▶ In Virginia, the average annual medical costs in 2005 for Medicaid-enrolled children with an ASD were \$10,709 per child, which was about six times higher than costs for children without an ASD (\$1,812).
  - In addition to medical costs, intensive behavioral interventions for children with ASDs cost \$40,000 to \$60,000 per child per year.
- ▶ A 2006 study by the Harvard School of Public Health indicates that the average lifetime cost to care for a person with ASD is \$3.2 million.

8

## Funding and Programs for Individuals with ASD (birth – 21)

Age	Program	Department/Office
0-5	Child Development Clinics	Department of Health
	Early Intervention Part C	Dept. of Behavioral Health and Developmental Services
	School Part B (2-5)	Department of Education
	Comprehensive Services Act	Office of Comprehensive Services
	Intellectual Disabilities Waiver	Dept. of Behavioral Health and Developmental Services
	Day Support Waiver	Dept. of Behavioral Health and Developmental Services
	Elderly Disabled Consumer Directed Waiver	Department of Medical Assistance Services
6-21	Child Development Clinics	Department of Health
	Early Intervention Part C	Dept. of Behavioral Health and Developmental Services
	School Part B	Department of Education
	Comprehensive Services Act	Office of Comprehensive Services
	Intellectual Disabilities Waiver	Dept. of Behavioral Health and Developmental Services
	Day Support Waiver	Dept. of Behavioral Health and Developmental Services
	Elderly Disabled Consumer Directed Waiver	Department of Medical Assistance Services
16-21	Vocational Rehabilitation	Department for Aging and Rehabilitative Services
	Woodrow Wilson Rehabilitation Center	Department for Aging and Rehabilitative Services
	Centers for Independent Living	Department for Aging and Rehabilitative Services

## Funding and Programs for Adults (22+) with ASD

Program	Department
<b>Medicaid Waivers</b>	
Intellectual Disabilities	Dept. of Behavioral Health and Developmental Services
Day Support	Dept. of Behavioral Health and Developmental Services
Individual & Family Developmental Disabilities	Department of Medical Assistance Services
Elderly Disabled Community Directed	Department of Medical Assistance Services
<b>Rehabilitation Programs</b>	
Vocational Rehabilitation	Department for Aging and Rehabilitative Services
Woodrow Wilson Rehab Center	Department for Aging and Rehabilitative Services
Centers for Independent Living	Department for Aging and Rehabilitative Services

## **Primary Needs of Adults with ASD**

- ▶ The primary needs for adults with ASD generally include:
  - Additional education or training
  - Adequate income to be self supporting which may involve:
    - Employment
    - Other support such as Supplement Security Income disability payments
  - Housing which may involve:
    - Non-supported, independent living
    - Group home
    - Congregate care facility
  - Health care services (including therapy of all types)
- ▶ With better interventions and supports across the lifespan, a person with ASD can achieve independence in medical, housing, employment and social needs.

11

## **Adults with ASD Age Out of Entitlement System**

- ▶ No entitlement services exist for adults with ASD
  - Services are guaranteed through age 21, but then the adult with ASD must voluntarily seek out services and meet eligibility requirements in order to receive services, which in turn are limited in availability.
- ▶ Primary sources of services for adults:
  - Medicaid waivers for community-based supports
  - Department for Aging and Rehabilitative Services (DARS) for employment supports

12

## Medicaid Waivers

- ▶ 5 of the 7 waivers are applicable to the ASD population:
  - Day Support Waiver for Individuals with Intellectual Disability (Day Support Waiver)
  - Elderly or Disabled with Consumer-Direction Waiver (EDCD Waiver)
  - Individual and Family Developmental Disabilities Supports Waiver (DD Waiver)
  - Intellectual Disability Waiver (ID Waiver)
  - Technology Assisted Waiver (Tech Waiver)

13

## Medicaid Waivers

- ▶ JLARC's report, *Assessment of Services for Virginians with Autism Spectrum Disorders* (HD8 – 2009), stated:
  - Medicaid waivers do not guarantee access to needed supports.
    - Enrollment is capped for most waivers
    - As of 2012, the ID Waiver Waiting List was 5,933 and the DD Waiver Waiting List was 1,078.
    - Only most severely disabled meet functional needs eligibility
  - Case management services not widely available to facilitate access to existing supports.
- ▶ Our review indicates this continues to be true.

14

## DOJ Settlement and Waiver Reform

- ▶ Under Virginia's Settlement Agreement with the U.S. Department of Justice, the Department of Behavioral Health and Developmental Services (DBHDS) will:
  - Expand case management capacity within community services boards (CSBs).
  - Plan jointly with the Department of Medical Assistance Services (DMAS) for waiver changes over the next 2 years.
    - Create 4,170 waiver slots by June 30, 2021.
    - Move to needs-based waivers (not ID/DD based)
      - Based on level of functionality and not diagnosis
    - Recommend needed rate changes to serve those with the most complex needs and align incentives

15

## TRANSITION PLANNING

16

## The Importance of Transition

- ▶ Students with ASDs have less favorable employment outcomes than students with other disabilities.
- ▶ Likewise, young adults on the autism spectrum are less likely to have ever lived independently after high school, than adults with other disabilities.

### Virginia ASD Transition Indicators (compared to all students with disabilities)

	2010	2011	2012
Advanced Diploma	51 (.5%)	54 (.5%)	51 (.5%)
Standard Diploma	99 (.9%)	106 (1.0%)	148 (1.4%)
Modified Diploma	23 (.2%)	22 (.2%)	35 (.3%)
Special Diploma	73 (.7%)	121 (1.2%)	97 (.9%)
Competitively Employed	29 (1.1%)	21 (.8%)	63 (1.6%)
Sheltered Employment	*	*	11 (.3%)
Employed, not competitively	92	109	124
2-4 Year College	110 (4.3%)	89 (3.6%)	123 (4.8%)
Training Program	*	18 (.3%)	14 (.2%)
Day Support	10	23 (.4%)	12 (.2%)
No participation in other postsecondary education or training program	54 (.9%)	69 (1.1%)	70 (1.1%)
Unengaged	33 (4.5%)	45 (5.3%)	41 (4.7%)
*fewer than 9			

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

- ▶ Requires public schools provide all students who require special education services, including those with ASD, a free and appropriate public education to meet their unique needs and prepare them for further education, employment and independent living.
- ▶ Mandates special education and related services to children ages two through 21 who have a disability that negatively impacts their access to the general curriculum.
- ▶ The IDEA requirements are facilitated through the Individualized Education Program (IEP) process, and this process must include transition planning by age 16.
  - In Virginia, all students with disabilities who have individualized education programs (IEPs) are required to develop a transition plan as a part of their IEP at the age of 14.

19

## **Transition Planning**

- ▶ Ideally, in order for children with ASD to achieve further education, training, employment and independent living, transition planning needs to be:
  - Commenced as early as possible
  - Outcome-oriented
  - Based upon the student's strengths, interests, preferences, and areas of need
  - Focused on instruction and services for education, training, employment, and other living skills, giving children more opportunities to develop these skills while they are still under IDEA.

20



## **Transition Team**

- ▶ The transition team should include:
  - The student (as appropriate)
  - The student's parents or guardians
  - Teachers (special and general education)
  - School administrators
  - Related service providers such as speech therapists, behavioral consultants, etc.
  - Representatives of outside agencies that may provide support to reach post-secondary goals, such as the Division of Vocational Rehabilitation within the Department for Aging and Rehabilitative Services
  - Other individuals who can support the student

21

## **2009 JLARC Report Also Addressed Transition Services**

- ▶ JLARC's report on services for individuals with ASDs found "transition planning and services may not address the unique needs of students with ASDs."
- ▶ JLARC recommended the Virginia Department of Education (VA DOE):
  - Develop transition guidelines
  - Create transition specialist positions
  - Expand vocational and life skills training.

22

## Virginia DOE Transition Guidelines

- ▶ The Virginia DOE has issued guidelines for transition planning which include:
  - Characteristics of excellent transition programs
  - Transition team composition
  - Transition assessment
  - Educational and transition planning
  - Instruction for transition age youth in natural environments
  - Addressing challenging behavior through positive behavior supports
  - Navigating adult services
  - Postsecondary education
  - Workplace challenges and supports
  - Home living skills
  - Recreation and leisure skills
  - Social Security and benefits planning

23

## Virginia DOE and Transition

- ▶ Have a case manager assigned to each person with an IEP.
- ▶ Have transition coordinators, in addition to the case managers, staffing larger school districts.
  - Match students with ASD with community resources.
  - Act as a liaison between the community service agencies and the students, their families, and education case manager.
- ▶ Have cooperative agreements in place between the local school and the local DARS field office.
- ▶ Place the responsibility of inviting other agencies, such as DARS or CSBs, to the transition meetings on the ASD families.

24

## Coordination and Collaboration

- ▶ The Virginia DOE issued transition guidelines rather than policy regulations in order to afford flexibility in meeting the varying needs of individuals with ASD.
- ▶ Successful transition planning is still dependent on where someone lives, in what school district, and the expertise and institutional knowledge of the persons who have been included on the transition team.
- ▶ Families report often DARS representative not involved in transition planning.
- ▶ Families are not the experts on ASD and community resource availability and should not be the ones determining which agency representatives should be at initial transition meetings.

25

## Coordination and Collaboration

- ▶ Even though DBHDS has become the lead agency for ASD-related services, families continue to report difficulty in navigating the system.
  - Many families continue to report they too often do not understand waivers or their options for financial assistance, employment, and housing.
- ▶ DBHDS is working with DMAS and stakeholders in designing an integrated Medicaid waiver for individuals with developmental disability
  - The new waiver is expected to “be more person-focused and needs-based than the three current waivers.” DBHDS *Creating Opportunities: Report of Accomplishments*, Dec. 2013, p. 4

26

## Case Management

- ▶ One of the goals of having DBHDS as the lead agency for ASD was to create collaboration and coordination and provide the opportunity to address service gaps.
- ▶ As indicated in the JLARC report, and it remains true, “case management services are not consistently available to coordinate the care of Virginians with ASDs”
  - Programs that offer case management are not consistent or comprehensive.

27

## Case Management

- ▶ Case management services only exist for adults enrolled in waivers or DARS programs.
- ▶ There needs to be collaboration between DOE, DARS, and CSBs to ensure adults with ASDs learn about and access available community resources as they transition.
- ▶ CSBs could take the lead in case management for adults with ASD, but they lack staff trained in the specific needs of individuals with ASD.

28

## Higher Education/Employment

29

### Virginia DOE Diplomas

- ▶ The Virginia DOE has created diplomas designed to assist individuals with any level of ASD to transition to higher education, training, and meaningful employment.
  - Advanced Diplomas are required for most four-year colleges and universities.
  - Standard Diplomas are generally required for community colleges.
  - Special Diplomas ensure a person has left school with a certain skill-set.
    - This gives individuals with ASD who will not seek higher education, the training necessary to have a vocation.

30

## Post-Secondary Education

- ▶ Depending on where a person is on the spectrum, post-secondary education is a realistic goal that can be successfully prepared for during transition.
- ▶ Although a student below the age of 22 will still qualify for federal funds, the local school districts are no longer in charge or part of the process.
  - The transition should assist the student in practicing self-determination; to be his/her own advocate and to seek out the supports needed and offered within the Disability Office of the post-secondary campus.

31

## ASD and Employment

- ▶ Employment provides the income to allow a person to live independently, but persons with ASD are employed at much lower rates than those with other disabilities.
  - ▶ According to the Southwest Autism Research and Resource Center, the unemployment rate for young adults with ASD is about 90 percent, nationally.
- ▶ Employment is a realistic goal for most if appropriate planning has taken place, and the appropriate level of supports are available across the lifespan.

32

## ASD and Employment

- ▶ For persons with more significant support needs, employment opportunities, training and services must be available so that competitive employment is realistic; employment opportunities, training and services are available to meet the needs of persons with ASD.
- ▶ These opportunities may not mean higher wages, but at a minimum, allow for employment in an integrated setting and involvement in the community.
- ▶ There are a number of employment models with varying degrees of support.
  - Working fully independently alongside nondisabled peers.
  - Constant or intermittent oversight by a job coach
  - Segregated employment—typically referred to as a sheltered workshop

33

## DARS Services

- ▶ DARS is the agency responsible for providing employment supports for individuals with ASD.
- ▶ DARS is seeing a steady increase in applications for services by people with ASDs.
  - In 2010, 1,029 people with ASDs were served, up from 737 in 2008.
  - In addition in 2010, 88% of those served were transition age youth. (but not all are ASD)
    - These individuals often have higher support needs and thus require more extensive vocational rehabilitation services than other individuals with disabilities served by DARS.
- ▶ Since the JLARC report, DARS has been working to improve vocational services for individuals with ASD in transition.

34

## **DARS Order of Selection**

- ▶ DARS has been operating under a federal Order of Selection in recent fiscal years because there were not sufficient funds to serve all eligible individuals.
  - New applicants who were determined eligible for services were placed on a waiting list according to disability categories.
  - Sometimes knowing there is an order of selection prevents persons from even applying for services to be put on the waiting list.
- ▶ At the end of FY 2012, there were 1,580 individuals on the waiting list for vocational rehabilitation programs.

35

## **Long-Term Support Services**

- ▶ Current DARS data show individuals with ASDs require higher levels of employment supports to achieve successful employment, and the lack of such supports remains a consistent complaint from individuals with ASD and their families.
- ▶ DARS administers the Long-Term Employment Support Services (LTESS) program to provide supported employment services to qualifying individuals beyond the 90 days allowed by the vocational rehabilitation program.
  - DARS contracts with private Employment Services Organizations to provide these long-term support services.
  - The program is funded exclusively with General Fund dollars and has the potential to ensure that individuals with ASDs, who need ongoing support, remain successfully employed.
  - Because funding for the program is capped, and is not disability specific, not all individuals who require long-term supports are able to receive them.
  - Additionally, this program has received significant funding cuts over the last several years.

36



## **Examples of DARS Programs and Services**

- ▶ The Woodrow Wilson Rehabilitation Center
  - The Life Skills Training Program has been expanded to meet the needs of more individuals with ASD.
- ▶ Postsecondary Education Rehabilitation Transition (PERT)
  - Provides special education high school students, 16 and older, a comprehensive evaluation in the areas of vocational skills, independent living skills, and leisure and social skills.

37

## **Other Employment Initiatives**

- ▶ Project SEARCH
- ▶ DBHDS Employment First Initiative
  - Virginia must provide integrated day activities and significantly shift the number of individuals in day support programs to integrated day opportunities, including supported employment.
  - Strategize on ways to reach out to business communities to educate and increase awareness of employing persons with disabilities.
  - Revise Waiver Day Support regulations to increase flexibility and emphasis on employment as the priority focus.

38

# Housing

39

# Housing

- ▶ Successful transitioning to independent living requires affordable and accessible housing, which continues to be inadequate in Virginia.
  - Because of the range of needs for those with ASD, a range of housing options needs to be available as well as an individualized living plan similar to the IEP.
- ▶ Currently the housing options with adequate services are limited and expensive, and funding and affordability of services and housing are major concerns.

40

## Current Housing Options

- ▶ The current housing options include:
  - Living independently
  - Living at home with family
  - Supported apartment living
  - Group homes
  - Supported independent living
  - Home sharing
  - Sponsored placement

41

## Transition to Housing

- ▶ The current waiver system is based on diagnosis and acts as a barrier to persons with ASD in finding housing.
  - Individuals with an intellectual disability and on the ID Waiver are eligible to receive in-home residential support in congregate group homes and congregate-sponsored services
    - Such support is not available for individuals served by the DD waiver as it does not address housing needs.
  - Through waiver reform as required by Virginia's settlement agreement with the Department of Justice, DBHDS will address this inconsistency and seek to improve housing options for individuals with ASD.

42

## **Transition to Housing**

- ▶ Affordable housing requires income, but many persons with ASD are unemployed and receive SSI payments.
- ▶ SSI is the baseline for financial support which typically is too low to allow a person to afford housing.
  - Paired with the difficulty in finding meaningful employment with a competitive wage, SSI often becomes a disincentive to find employment and the individual with ASD will continue to live in the family home.

43

## **DBHDS Current Housing Efforts and the DOJ Settlement**

- ▶ The DOJ Settlement requires DBHDS
  - To serve individuals in the most integrated setting consistent with their informed choice and needs and
  - To include a term in the performance contract with CSBs to require case managers to continue to offer education about less restrictive community options on at least an annual basis to any individual living outside their own home or family's home.
  - To assemble baseline information regarding the number of individuals who would choose independent living options
  - To develop a plan to increase access to independent living options
  - To undertake a \$800,000 rental assistance pilot in an effort to address these housing needs.

44

## Policy Options

45

## Policy Options

**Option 1:** Take no action.

**Option 2:** By letter of the JCHC Chair, encourage the Department of Behavioral Health and Developmental Services to publicize its role as lead agency for services for individuals with ASD and to highlight the link to Commonwealth Autism Services as a valuable resource on ASD information, including information related to transition services.

**Option 3:** Introduce a budget amendment (amount to be determined) to expand the case management services provided by the Department for Aging and Rehabilitative Services in order to address the increasing demand for ASD services and to enable more consistent involvement in transition planning.

**Option 4:** Introduce a budget amendment (amount to be determined) for the Department of Behavioral Health and Developmental Services to allow community services boards (CSBs) to be involved with transition planning and provide case management services for adults with ASD (after the Department of Education is no longer involved).

46

## Policy Options

**Option 5:** By letter of the JCHC Chair, request that the Department of Behavioral Health and Developmental Services work to improve collaboration between its agency, the Department for Aging and Rehabilitative Services, and community services boards for ASD-related services for adults (beginning with transition planning).

**Option 6:** By letter of the JCHC Chair, request that the Department of Behavioral Health and Developmental Services form a stakeholder workgroup to develop CSB-staff competencies for providing case management for adults with ASD.

**Option 7:** Introduce a budget amendment (amount to be determined) to expand Long-Term Employment Support Services administered by the Department for Aging and Rehabilitative Services.

**Option 8:** By letter of the JCHC Chair, request that the Joint Legislative Audit and Review Commission conduct a follow-up to its 2009 report on ASD and consider our findings in completing the study.

47

## Public Comment

- ▶ Written public comments on the proposed options may be submitted to JCHC by close of business on October 8, 2013.
- ▶ Comments may be submitted via:
  - E-mail: [jhoyle@jhc.virginia.gov](mailto:jhoyle@jhc.virginia.gov)
  - Fax: 804-786-5538
  - Mail: Joint Commission on Health Care  
P.O. Box 1322  
Richmond, Virginia 23218
- ▶ Comments will be summarized and reported during the October 22<sup>nd</sup> meeting.

▶ Website – <http://jhc.virginia.gov>

48

13102554D

SENATE JOINT RESOLUTION NO. 330

Offered January 9, 2013

Directing the Joint Commission on Health Care to study service needs of individuals with autism and autism spectrum disorders transitioning from secondary schools. Report.

Patron—Northam

Referred to Committee on Rules

WHEREAS, autism and autism spectrum disorders are a group of developmental disabilities, characterized by atypical development in socialization and behavior, with associated impairments affecting multiple areas of an individual's life; and

WHEREAS, according to the Centers for Disease Control and Prevention, an estimated 1 in 88 children have an autism spectrum disorder; and

WHEREAS, according to the Virginia Department of Education, in 2011, approximately 11,700 Virginia students were identified with an autism spectrum disorder; and

WHEREAS, the prevalence rate of autism has increased significantly in Virginia and across the country in recent years; and

WHEREAS, individuals with an autism spectrum disorder may require or may benefit from special educational, housing, employment, and other supports and services; now, therefore, be it

RESOLVED by the Senate, the House of Delegates concurring, That the Joint Commission on Health Care be directed to study service needs for individuals with autism and autism spectrum disorders transitioning from secondary schools.

In conducting its study, the Joint Commission on Health Care shall determine the number of individuals with autism graduating from or aging out of public and private secondary schools; identify the specific service needs of such individuals, including needs related to housing, employment support, and day support services; identify current sources of services and assistance for such individuals; and identify gaps in the service system or service needs.

All agencies of the Commonwealth shall provide assistance to the Joint Commission on Health Care for this study, upon request.

The Joint Commission on Health Care shall complete its meetings by November 30, 2013, and the Chairman shall submit to the Division of Legislative Automated Systems an executive summary of its findings and recommendations no later than the first day of the 2014 Regular Session of the General Assembly. The executive summary shall state whether the Joint Commission on Health Care intends to submit to the General Assembly and the Governor a report of its findings and recommendations for publication as a House or Senate document. The executive summary and report shall be submitted as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents and reports and shall be posted on the General Assembly's website.

INTRODUCED

SJ330

Joint Commission on Health Care  
900 East Main Street, 1st Floor West  
P. O. Box 1322  
Richmond, VA 23218  
804.786.5445  
804.786.5538 (fax)

Website: <http://jchc.virginia.gov>