Report of the
Joint Legislative Audit and Review Commission
To the Governor and
The General Assembly of Virginia

Assessment of Services For Virginians With Autism Spectrum Disorders

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In Brief

Assessment of Services For Virginians With Autism Spectrum Disorders

House Joint Resolution 105 from the 2008 General Assembly directed JLARC staff to examine the services available to Virginians with autism spectrum disorders (ASDs) in the Commonwealth.

JLARC staff found that while several public programs exist to diagnose, treat, and manage ASDs, those tend to be inadequately coordinated and cannot fully meet the needs of Virginians.

Although the research literature indicates that ASDs can be diagnosed between ages two and three, many children in the State are diagnosed later. Early intervention programs frequently do not provide the intensity of services needed to maximize outcomes and minimize costs, and many Virginia schools lack the tools and training to fully address the needs of students with ASDs. Limited supports exist to help adults with ASDs achieve independence.

If Virginia chooses to improve its system of care, priority could be given to ensuring that resources are used efficiently and services delivered effectively. Service gaps could then be alleviated, starting with early intervention.

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August 5, 2009

The Honorable M. Kirkland Cox
Chairman
Joint Legislative Audit and Review Commission
General Assembly Building
Richmond, Virginia 23219

Dear Delegate Cox:

House Joint Resolution 105 of the 2008 General Assembly directed staff of the Joint Legislative Audit and Review Commission to study autism services in the Commonwealth. Specifically, staff were directed to assess the availability and delivery of services to Virginians with autism spectrum disorders (ASDs), examine the provision of these services in other states, and identify ways to better serve individuals with ASDs in the Commonwealth.

Staff findings were presented to the Commission on June 8, 2009, and are included in this report.

On behalf of the Commission staff, I would like to thank the staff at the Departments of Behavioral Health and Developmental Services, Education, Medical Assistance Services, Rehabilitative Services, and Health, as well as the Board for People With Disabilities and Commonwealth Autism Service for their assistance during this study.

Sincerely,

Philip A. Leone
Director

PAL/nmr

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JLARC Report Summary:

Assessment of Services for Virginians With Autism Spectrum Disorders

Key Findings

- Several treatment approaches have been found to substantially improve the outcomes of individuals with autism spectrum disorders (ASDs). In particular, intensive early intervention services can significantly reduce the costs associated with special education and other public supports. (Chapter 2)

- Virginia operates several publicly supported programs through various agencies to help diagnose, treat, and manage ASDs. However, these programs do not form a comprehensive system of care and must often be supplemented by privately secured services. (Chapter 3)

- State programs supporting individuals with ASDs tend to be inadequately coordinated. While the Department of Behavioral Health and Developmental Services will begin orchestrating existing programs in July 2009, no State entity has held this role previously. In addition, no comprehensive source of information exists to educate Virginians about ASDs and available services, and case managers are not consistently available to facilitate access to care. (Chapter 4)

- Although the research literature indicates that ASDs can be diagnosed between ages two and three, it appears that Virginia children are often diagnosed later and may therefore experience delays in receiving early intervention services. (Chapter 5)

- Early intervention programs serving young children with ASDs do not always include components that have been shown to yield positive outcomes, such as providing intensive interventions and using research-based practices. (Chapter 6)

- Many Virginia schools lack the guidance, training, and tools needed to uniformly meet the multifaceted needs of students with ASDs or adequately prepare them for future independent living. (Chapter 7)

- To achieve some measure of independence and productivity, many adults with ASDs require ongoing services and supports that are not widely available in Virginia, and may have to rely instead on public assistance programs. (Chapter 8)

- While public safety personnel may need specialized knowledge to properly address situations involving persons with ASDs, limited training opportunities are available, and most are offered only to law enforcement agencies. (Chapter 9)

- If Virginia chooses to improve its system of care, priority could be given to ensuring that resources are used efficiently and services delivered effectively. Service gaps could then be addressed, especially in early intervention. (Chapter 10)

Virginia has experienced a dramatic increase in the number of children diagnosed with autism spectrum disorders (ASDs) during the last decade. ASDs are lifelong developmental disabilities that usually manifest themselves before the age of three and affect social interactions, communication, and behavior. Stakeholders have expressed concerns that the State's current service delivery system may not be keeping pace with growing needs for diagnosing, treating, and managing ASDs. Furthermore, the rising prevalence of ASDs has raised questions about the ability of public safety personnel to properly respond to emergency and legal situations involving persons with ASDs.

In response to these concerns, the 2008 General Assembly enacted House Joint Resolution 105, which directs staff of the Joint Legislative Audit and Review Commission (JLARC) to assess the availability and delivery of ASD services in the Commonwealth, examine the provision of these services in other states, and identify ways to better serve individuals with ASDs in Virginia. In addition, the mandate directs JLARC staff to determine the extent to which public safety personnel are currently trained and educated about ASDs and to identify training best practices employed in other states.

ASDs CAN OFTEN BE EFFECTIVELY TREATED, RESULTING IN COST SAVINGS

Several treatment approaches have been scientifically shown to meaningfully improve the outcomes of individuals with ASDs, including the commonly referenced applied behavioral analysis (ABA) method. In particular, most young children with ASDs who participate in intensive early intervention programs based on ABA principles experience improvements, with almost half achieving normal levels of functioning and an additional 40 percent realizing moderate gains. According to cost-benefit analyses, providing intensive treatment to young children can significantly reduce public costs by decreasing the need for special education and other forms of public assistance, with savings likely to accrue over the lifetime of individuals with ASDs. While many approaches have been categorized as effective for treating ASDs, research indicates that packaged programs with a pre-determined curriculum, such as ABA, appear to have more promising results than programs that rely on a more informal mix of interventions.

SEVERAL PUBLICLY SUPPORTED PROGRAMS ASSIST VIRGINIANS WITH ASDs AND THEIR FAMILIES

Virginia operates several publicly supported programs to help diagnose, treat, and manage ASDs through various agencies, as summarized in the table on the following page. Young children can receive early intervention services through Part C of the federal Individuals with Disabilities Education Act (IDEA), while schools administer Part B of IDEA, which entitles children ages two through 21 to supports and services necessary to obtain an appropriate education and ultimately achieve independence. The State has also implemented four Medicaid waiver programs that offer supports to persons with developmental disabilities of all ages. Beyond waivers, services available to adults with ASDs are limited primarily to employment supports and vocational training.

While they represent a valuable resource for eligible individuals, existing programs do not constitute a comprehensive system of care that fully meets the needs of all individuals with ASDs. Many Virginia families report supplementing publicly supported programs, but their personal resources are often insufficient to pay for extensive and lifelong services, and health insurance policies do not consistently or comprehensively cover ASD-related therapies.

List of Major Publicly Supported Programs Serving Virginians With ASDs, by Agency

Department / Office	Program
Health	Child Development Clinics
Medical Assistance Services	Individual and Family Developmental Disabilities (DD) Support Waiver
	Elderly or Disabled with Consumer Direction (EDCD) Waiver
Behavioral Health and Developmental Services [a]	Mental Retardation (MR) Waiver
	Day Support Waiver
	Early Intervention Part C
Education	School Part B
Comprehensive Services	Comprehensive Services Act (CSA)
Rehabilitation Services	Vocational Rehabilitation
	Woodrow Wilson Rehabilitation Center
	Centers for Independent Living (CILs)

[a] Formerly Mental Health, Mental Retardation and Substance Abuse Services.

Source: JLARC staff interviews with agency personnel and review of agency documentation.

VIRGINIA SYSTEM COULD BE BETTER COORDINATED

Although multiple programs and funding sources support Virginians with ASDs, they tend to be inadequately coordinated at the State, community, and individual levels. No State entity has, to date, orchestrated the efforts of the complex network of agencies and programs described above. As a result, Virginia has lacked a mechanism through which to develop public policy that supports its vision for serving individuals with ASDs, ensure that resources are used as efficiently as possible across programs and agencies, promote the effectiveness of services, and address service gaps.

However, the Department of Behavioral Health and Developmental Services (BHDS) will assume lead responsibility for coordinating services in July 2009, and this appears to be an appropriate choice of agency.

The State also does not make available a centralized, reliable source of information that enables Virginians to identify ASD-related programs and funding sources available in their communities. In addition to being burdensome, the lack of centralized information may preclude families from fully understanding ASDs, seeking treatment that is effective, locating reputable providers who can successfully manage their condition, or accessing public programs and supports for which they are eligible. Furthermore, individuals with ASDs do not consistently have case managers who can facilitate access to needed programs and services. As a result, individuals with ASDs and their caregivers are often the primary coordinators of services across programs and providers. However, neither the individuals with ASDs nor their caregivers may consistently possess the skills and resources to adequately fulfill this function.

Virginia could consider several options to improve coordination and help build a more cohesive system of care. First, BHDS may need to prioritize its initiatives in order to fulfill its new mission as successfully and seamlessly as possible, given limited resources. In addition, the State should create a centralized, comprehensive source of information to help Virginians with ASDs and their families make informed decisions about needed services and access existing programs. Lastly, comprehensive case management services could be made available to all persons with ASDs to ensure the most efficient and effective use of resources and facilitate access to care.

INDIVIDUALS WITH ASDs MAY NOT BE DIAGNOSED AS EARLY AS POSSIBLE

While the research literature indicates that ASDs can be diagnosed between ages two and three, it appears that Virginia children are often diagnosed later. Identifying and diagnosing ASDs at young ages enables children to begin receiving ASD-specific early intervention services, which research shows can produce favorable outcomes. Delays appear to occur because parents are uncertain how to proceed when they notice signs of atypical development; physicians do not consistently use recommended screening practices; diagnostic capacity is limited, especially in multidisciplinary environments; and parents and providers often lack information about obtaining services after an ASD screening or diagnosis.

To facilitate earlier identification and diagnosis for Virginians with ASDs, information could be provided to better equip individuals to recognize early signs of ASDs and to pursue a diagnosis and services. In addition, Virginia could help professionals with identification and diagnosis by providing training on performing screenings to medical and non-medical personnel, creating regional capacity to provide multidisciplinary diagnoses, and training pediatricians to make these diagnoses. The referral process could also be improved by providing more information to physicians and facilitating the creation of comprehensive plans of care.

VIRGINIA PROGRAMS SERVING YOUNG CHILDREN WITH ASDs LACK KEY COMPONENTS AND FACE SERVICE DELIVERY LIMITATIONS

Programs with primary responsibility for providing early intervention services to Virginians with ASDs do not consistently emphasize or implement the key components of effective programs identified in the research literature. For example, the Early Intervention Part C program serving Virginians from birth through age two does not emphasize providing services in a structured environment, and the School Part B preschool programs serving children ages two to five do not emphasize involving families in activities beyond service planning, such as training them on interventions. Neither of these two programs formally recognizes the importance of providing intensive services to young children with ASDs, nor do they consistently provide interventions that have been proven effective for this population or employ staff with expertise in ASDs.

Eligible children with ASDs can also obtain early intervention services through Virginia's Medicaid program, but service delivery limitations impact their ability to access needed care. Waiting lists delay enrollment by several years, and access to ASD-related interventions is limited even for those who are enrolled. In addition, families and providers appear largely unaware that children enrolled in waivers can access specialized ASD-related interventions that are medically necessary through the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program. Families also do not commonly use the Elderly or Disabled with Consumer Direction waiver program, which does not have a waiting list and could allow them to access medically necessary services (such as ABA) through EPSDT.

To improve the early intervention system for young children with ASDs, steps could be taken to increase the knowledge and qualifications of early intervention providers and promote the use of outcome measures. In addition, the intensity of services delivered through existing programs could be enhanced. Families should be better informed about the availability of Medicaid-funded services.

Regional offices such as community services boards (CSBs) could be used to deliver direct services that are insufficiently available from existing programs, although CSBs already face challenges in serving existing populations.

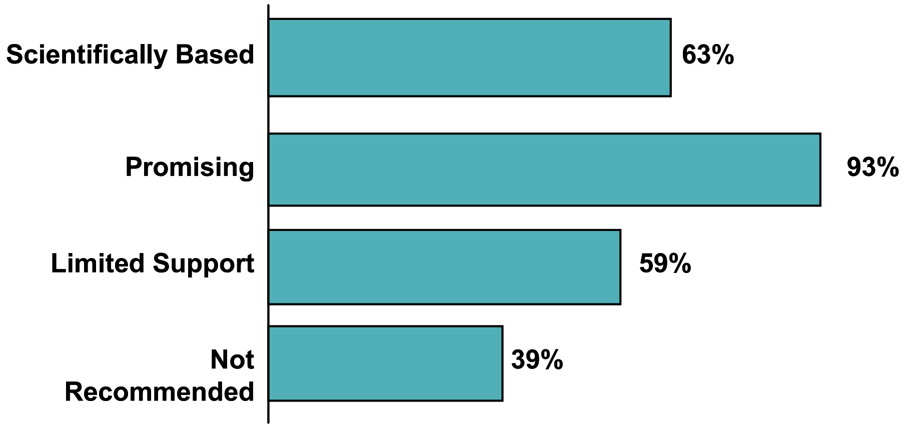
MOST SCHOOLS ARE UNABLE TO FULLY MEET THE NEEDS OF STUDENTS WITH ASDs

While Virginia schools report generally being able to provide an appropriate education to children with ASDs, it appears that most struggle to fully meet these students' multifaceted needs and prepare them for independent living. Schools generally succeed in meeting process requirements such as providing adequate inclusion opportunities, offering services in an appropriate setting, and including parents in the individualized education program process. In addition, the State has taken several steps to help schools more effectively serve students with ASDs, such as creating service guidelines and identifying the skills needed by providers, and many local school divisions have built ASD expertise through training and partnerships.

While these efforts show promise, many schools currently report being unable to shape outcomes by addressing the core deficits of ASDs, providing instruction that allows students to generalize skills to settings other than schools, and ultimately reducing the need for special education services. Although federal law and best practices emphasize the importance of using interventions that have been proven effective for students with ASDs, more than one-third of Virginia schools responding to a JLARC staff survey do not rely on scientifically based practices, as shown in the figure on the following page. In addition, nearly 40 percent of responding schools report using interventions that have been labeled by experts as "not recommended" for use with students with ASDs. Schools do not appear to consistently collect the data needed to track students' progress and alter programming.

The challenges faced by Virginia schools in fully meeting the needs of students with ASDs stem, in part, from insufficient training and technical assistance. While the State's network of special education Training and Technical Assistance Centers (T/TACs) is an important resource, it does not appear to provide the type and intensity of training that schools report needing. In fact, schools consistently identified gaps in professional development and access to outside experts as key barriers to their ability to serve students with ASDs. Although many schools have developed local ASD expertise, this is not the case statewide. Still, schools with access to a division-level ASD expert reported a greater ability to meet the needs of students on the autism spectrum.

More Than One-Third of Responding Schools Report Not Using Scientifically Based Interventions To Serve Students With ASDs



Note: Percentages reflect the proportion of responding schools using at least one intervention falling into any of the categories.

Source: JLARC staff survey of a sample of Virginia public schools, February 2009.

In addition to addressing academic instruction, the ability of schools to develop social, life, and vocational skills is critical to shaping the outcomes of students with ASDs after they leave the school system. Although the federal government emphasizes the provision of services that prepare students with disabilities for future independent living, less than one-third of Virginia high schools responding to a staff survey reported being able to provide services that further this goal.

Moreover, the caregivers of individuals with ASDs reported that insufficient vocational and job skills training through schools were key barriers to their children's independence once out of school. Schools' inability to adequately prepare students with ASDs for post-school life appears due to a transition planning process that does not consistently account for the core behavioral, social, and communication deficits of ASDs, as well as a lack of positions dedicated to developing and implementing transition plans and services.

To improve the delivery of services to school-age children with ASDs, Virginia could build upon existing State and local initiatives to address its professional development programs, increase the qualifications of school personnel, make ASD experts more consistently available, and create a statewide training agenda. In addition, steps could be taken to improve the ability of school staff to develop appropriate goals and use data to make programming decisions. Virginia could also improve transition planning through guidelines and transition specialists, and expand the availability of services aimed at building life and vocational skills.

VIRGINIA PROGRAMS SUPPORTING ADULTS WITH ASDs DO NOT MAXIMIZE INDEPENDENCE

To achieve the greatest possible degree of independence and productivity, many adults with ASDs require ongoing supports and services that are often lacking in Virginia. Only seven percent of adults with ASDs reported having maximized their independence in a JLARC staff survey. Although 85 percent of respondents identified employment as a realistic option, only one-third were employed, and two-thirds were relying on some form of public assistance.

Virginia's Department of Rehabilitative Services (DRS) is unable to consistently provide the types and intensity of services and supports required for individuals with ASDs to become successfully employed. First, some individuals with ASDs may not be able to access the social and communication skills training needed to be considered employable. Further, there is limited funding for long-term supports often required by persons with ASDs to maintain employment. Other barriers to employment include a lack of ASD-specific training among DRS counselors and a limited number of job coaches, waiting lists for DRS services, and an insufficient supply of employers willing or trained to hire individuals with ASDs. Yet, DRS data indicate that individuals with ASDs who secure a job tend to remain employed longer than other clients.

While employment supports are critical to the ability of adults with ASDs to engage in society as productive individuals, other supports may be needed to facilitate their highest possible degree of independence. Survey results indicate that additional housing, transportation, and community-based supports are needed for adults with ASDs. While some public programs exist, they are limited and cannot meet current demand. In particular, Medicaid waivers offer comprehensive, community-based services and supports, but not all adults are eligible, provider shortages exist, and the waiver for persons with developmental disabilities (DD) does not cover congregate care provided in community-based settings. In addition, Virginia's 16 Centers for Independent Living offer useful services, but are subject to funding constraints and do not appear to be commonly utilized by persons with ASDs.

To ensure that Virginia has a system of care in place for individuals with ASDs across all life stages, ASD-specific training could be made available to DRS staff who provide employment services, and additional resources could be dedicated to expanding the department's capacity to serve clients with ASDs. A review of Medicaid reimbursement rates and the feasibility of covering congregate care through the DD waiver could also be undertaken. In addition, the State could address the unique needs of adults with ASDs through its Olmstead implementation team, consistently provide case management services, and pilot a comprehensive program addressing the critical needs of adults with ASDs.

LIMITED ASD TRAINING OPPORTUNITIES EXIST FOR PUBLIC SAFETY PERSONNEL IN VIRGINIA

While public safety personnel require a certain level of awareness in order to properly address situations involving individuals with ASDs and avoid potentially harmful consequences, training opportunities are limited in Virginia. Fewer than half of Virginia's criminal justice academies responding to a JLARC staff survey report providing some type of ASD awareness training to law enforcement officers. Academies that do not provide ASD training indicate that they have either never considered providing such training, or opted not to implement it because this type of training is not required by the State. ASD awareness training is offered on an ad-hoc basis through in-service sessions for emergency medical services (EMS) and fire personnel, and no systematic training is available to judicial personnel.

If Virginia wishes to improve training among public safety personnel, a variety of tools could be used, ranging from a carry-card to an in-depth training course. While all public safety officers could benefit from ASD awareness training, priority could be given to law enforcement officers. The State could either require or simply encourage public safety agencies to make ASD training available.

SYSTEM COULD BE IMPROVED BY ENHANCING EFFICIENCY, IMPROVING EFFECTIVENESS, AND ADDRESSING SERVICE GAPS

Existing Virginia programs do not fully meet the needs of Virginians with ASDs who have extensive impairments, require supports from programs that have limited funding, or fail to meet eligibility criteria. If Virginia chooses to build a more effective and comprehensive system of care for these individuals, priority could be given to ensuring that existing resources are used as efficiently as possible and publicly supported programs have the tools to deliver effective services. Service gaps could then be addressed for individuals with ASDs who are currently unserved or underserved. In particular, intensive early intervention services could be provided because research has shown that they offer the greatest potential for improving outcomes and reducing future State expenditures. To achieve meaningful improvements while recognizing fiscal constraints, the State could build upon several existing initiatives, implement pilot projects, and focus on specific aspects of the service delivery system.

STATE COULD EXPLORE MULTIPLE FUNDING SOURCES IF OPTIONS ARE IMPLEMENTED

While Virginia may choose to use general funds to implement options it wishes to exercise, the role of other public and private sources could also be explored to share the cost of better meeting the needs of Virginians with ASDs and their families in a fair and appropriate manner. In particular, the State could

- expand Medicaid programs and receive federal matching funds for 50 percent of expenditures;
- launch pilot programs using short-term funding from the federal American Recovery and Reinvestment Act and subsequently expand initiatives that successfully address the needs of Virginians with ASDs;
- reinvest savings derived from efforts to either increase the efficiency of existing programs or alleviate service gaps, especially in the early intervention system;
- re-examine the extent to which localities should support program expenditures or require local matching funds for new services;
- enact legislation requiring health insurers to offer comprehensive coverage for ASD-related services; and
- require the contribution of personal resources based on an individual's ability to pay.

Chapter 1

Overview of Autism Spectrum Disorders

In Summary

Autism spectrum disorders (ASDs) are lifelong pervasive developmental disorders that generally manifest themselves by age three and typically impair individuals' social interactions, communication, and behavior. The autism spectrum includes autistic disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger's syndrome. Research has not yet identified what causes ASDs. Once thought to be relatively rare disorders, the Centers for Disease Control and Prevention now estimates that one out of every 150 eight-year-old children has an ASD. The cause of this increased prevalence is uncertain, but is commonly attributed to a combination of factors, including diagnostic substitutions for other conditions, broader diagnostic criteria, and a true rise in incidence. A variety of services are used to help individuals improve their level of functioning, including general and ASD-specific interventions, medications, and alternative therapies.

During the past decade, the number of children with autism spectrum disorders (ASDs) has increased dramatically in Virginia as well as in the rest of the nation. Most states are just beginning to explore ways to meet the rising demand for specialized services and supports needed to address these lifelong conditions. In fact, nearly all states have recently assembled a group tasked with identifying the key issues facing individuals with ASDs, and determining how well positioned public programs are to address them. In Virginia, stakeholders have expressed concerns that the current service delivery system is not keeping pace with growing needs for diagnosing, treating, and managing ASDs. Furthermore, the rising prevalence of ASDs has raised questions about the ability of public safety personnel to properly respond to emergency and legal situations involving persons with ASDs.

In response to these concerns, the 2008 General Assembly enacted House Joint Resolution 105 (HJR 105), which directs staff of the Joint Legislative Audit and Review Commission (JLARC) to assess the availability and delivery of autism services in the Commonwealth, examine the delivery of ASD services in other states, and recommend ways to improve delivery of these services in Virginia (Appendix A). In addition, the mandate directs JLARC staff to identify the extent to which public safety personnel are currently trained and educated about ASDs and to identify best practices employed in other states.

DSM-IV Definition of ASDs

The fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) defines the autism spectrum as including autistic disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger's syndrome. DSM-IV excludes other pervasive developmental disorders such as Rett's syndrome and childhood disintegrative disorder (CDD). This report will adhere to DSM-IV's definition of ASDs, unless otherwise noted.

WHAT ARE AUTISM SPECTRUM DISORDERS?

Autism spectrum disorders (ASDs) generally impair a person's social interactions, communication, and behavior. ASDs are considered pervasive developmental disorders: pervasive because they affect multiple areas of functioning, and developmental because they typically manifest prior to age three and have been seen as lifelong. The autism spectrum ranges from a milder form, Asperger's syndrome, to a severe form, autistic disorder. The cause of ASDs is unknown.

Characteristics of ASDs

Autism spectrum disorders are developmental disabilities that usually manifest themselves before the age of three and affect social interactions, communication, and behavior. The level of impairment and manifestations of ASDs varies greatly among individuals based on their specific disorder, age, and developmental level. However, a number of characteristics are often shared. For example, most individuals will experience some social impairments, such as not responding to a parent's smile or facial expressions, not showing concern for others, or not bringing objects to show parents just to share interest. Individuals with ASDs often have difficulties interacting socially with others and interpreting social gestures and non-verbal communication such as facial expressions. This can lead to limited social relationships, inappropriate social responses, and social isolation.

Individuals with ASDs may also exhibit some unusual behaviors, such as rocking back and forth, spinning, walking on their toes, or flapping hands. Furthermore, children with ASDs may experience delays in speech and language development. They may repeat exactly what others say without understanding meaning (echolalia), or not respond to their name. Individuals who exhibit few or mild ASD impairments are sometimes referred to as "high-functioning," while "low-functioning" persons tend to be more severely impaired. The breadth of ASD symptoms generally affects individuals' ability to function in all settings, including home, school, work, and the community.

Disorders Included in the Autism Spectrum

The autism spectrum is comprised of three disorders: autistic disorder (also known as classic autism, early infantile autism, childhood autism, or Kanner's autism), pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger's syndrome. To be diagnosed with an ASD, individuals must demonstrate some, but not all, social impairments, language impairments, and behavioral characteristics (Figure 1). The three types of ASDs are differ-

Figure 1: Differentiating Between Disorders on the Autism Spectrum

Characteristics	Diagnostic Criteria	Asperger's Syndrome	PDD-NOS	Autistic Disorder
Social Impairments	• Impairment in use of non-verbal behaviors • Failure to develop peer relationships • Lack of spontaneously sharing interests with others • Lack of social or emotional reciprocity	Meets at least 2 of the criteria	Meets unspecified number of criteria among these categories	Meets at least 2 of the criteria
Language Impairments	• Delay in or lack of spoken language • Inability to initiate or sustain conversations • Stereotyped or repetitive use of language • Lack of spontaneous make-believe or imitative play	Meets none of the criteria		Meets at least 1 of the criteria
Behavioral Characteristics	• Preoccupation with interests abnormal in focus or intensity • Inflexible adherence to specific nonfunctional routines or rituals • Stereotyped and repetitive motor manners (hand flapping) • Persistent preoccupation with parts of objects	Meets at least 1 of the criteria		Meets at least 1 of the criteria
Age of Onset		Unspecified	Usually after age 3	By age 3
Other		No clinically significant delay in language, cognitive development, adaptive behavior, or curiosity	Does not meet full criteria for autistic disorder, symptoms may be atypical	Must meet at least 6 total criteria among the social, language, and behavioral categories

Source: JLARC staff analysis of information from the Autism Society of America and Centers for Disease Control and Prevention.

entiated based on the severity of symptoms, age of onset, and occurrence of developmental delays, as indicated in Figure 1. For example, the symptoms of autistic disorder and PDD-NOS are similar, but tend to be less severe and occur after age three among individuals diagnosed with PDD-NOS. One of the key differences between Asperger's syndrome and the other ASDs is the lack of delays in language or cognitive development.

Causes of ASDs

While the medical community appears to agree that ASDs result from abnormalities in brain structure or function, the underlying causes of these abnormalities, and thus why ASDs occur, are unknown. A variety of theories have been put forward to explain the occurrence of ASDs. Most of these theories posit either a genetic or an environmental basis, while some researchers have advanced that a combination of genetic susceptibility and environmental triggers is responsible for these disorders. Currently, there is no conclusive evidence regarding the specific causes or triggers of ASDs.

Potential Genetic Causes of ASDs. Theories suggesting that ASDs are linked to genetic factors appear to be supported by a variety of evidence. First, family studies have found that parents with one child diagnosed with an ASD have an increased chance of having another child with an ASD diagnosis. Second, the identical twin of an individual with an ASD has a 90 percent chance of also having an ASD, while a fraternal twin also has an increased likelihood of having an ASD, albeit much lower than that of an identical twin. Additionally, the risk of ASDs recurring in the younger siblings of children with ASDs is between five and ten percent. Another indication that ASDs may have a genetic cause is the greater likelihood for males to have ASDs than females: males are four times more likely than females to have an ASD.

A relationship also appears to exist between certain genetic conditions and ASDs. According to the Centers for Disease Control and Prevention (CDC), individuals with fragile X syndrome, an inherited form of intellectual disability, are more likely to have an ASD; approximately one-third of all people diagnosed with fragile X syndrome are also diagnosed with ASDs. Another genetic disorder that appears to be commonly associated with ASDs is tuberous sclerosis, a condition which causes tumors to grow in the brain and other organs. Studies indicate that between 25 and 50 percent of all children with tuberous sclerosis also have an ASD.

Despite these clues that there is a genetic component to ASDs, research has yet to identify the specific genes responsible for these disorders. In fact, some theories posit that while a genetic abnormality may put persons at increased risk for developing ASDs, it alone does not cause the ASD. Rather, these theories contend that environmental factors trigger the genetic vulnerability.

Potential Environmental Causes of ASDs. Some theories advance that ASDs result from exposure to environmental factors such as pesticides, infectious diseases, or metals (particularly mercury or lead). Several organizations (including the CDC, National Institutes of Health, and U.S. Environmental Protection Agency or EPA) have been funding studies to investigate potential environmental causes of autism. One study, the Childhood Autism Risks from Genetics and the Environment (CHARGE), is investigating how environmental factors and gene-environment interactions affect neurodevelopment. With an aim of studying 1,000 to 2,000 children, CHARGE will be the largest epidemiologic study of confirmed ASD cases. However, many of these studies of environmental causes are still in progress (such as CHARGE), and no definite conclusions can be drawn about the role of environmental factors in ASDs.

National Vaccine Injury Compensation Program (VICP)

VICP is a federal program that allows individuals who believe they have suffered injury as a result of a vaccine to file a petition for compensation with the United States Court of Federal Claims. The petition is served to the Secretary of Health and Human Services, and trial judges make rulings in the cases. VICP was established in 1986 to prevent tort liability from threatening the availability of vaccines.

One of the most pervasive theories regarding the cause of ASDs is the link to childhood vaccinations. In particular, this theory posits that either the measles, mumps and rubella (MMR) vaccine itself causes ASDs, or that the thimerosal (a mercury-containing preservative) contained in some vaccines prior to 2001 causes ASDs. A variety of large-scale scientific studies have, however, concluded that there is insufficient evidence to establish a link between ASDs and either MMR vaccines or thimerosal. Despite the lack of scientific evidence, the vaccination theory has been so prevalent that 43 percent of the 12,850 cases filed with the National Vaccine Injury Compensation Program (VICP) have been brought forth by families claiming that a vaccine had caused their child's ASD between the court's establishment in 1986 and January 2009. In February 2009, the trial judges in three test cases found that there was no causal link between the receipt of vaccines and ASDs, and rejected the families' claims.

WHAT IS THE PREVALENCE OF AUTISM SPECTRUM DISORDERS?

According to data released by the CDC in 2007, one out of 150 eight-year-old children (0.67 percent) has an ASD diagnosis in the United States.

According to data released by the CDC in 2007, one out of 150 eight-year-old children (0.67 percent) has an ASD diagnosis in the United States. According to CDC's data, ASDs are more prevalent than most other developmental disorders, except intellectual disabilities (Table 1). The prevalence of ASDs is considerably higher than in years past, but it is unclear to what extent the increase is attributable to better diagnostic capabilities, expanded definitions of ASDs, or true changes in incidence.

Table 1: Prevalence Rate of ASDs Is Higher Than Several Other Developmental Disorders (2000)

Condition	Prevalence Rate
Intellectual disability	1 out of 83
Autism Spectrum Disorders	**1 out of 154**
Cerebral palsy	1 out of 323
Hearing loss	1 out of 833
Vision impairment	1 out of 833

Source: CDC National Center on Birth Defects and Developmental Disabilities, Metro Atlanta Developmental Disabilities Surveillance Program Surveillance Year 2000, JLARC staff analysis.

Estimated Prevalence of ASDs

The one out of every 150 ASD prevalence rate is based on surveillance activities conducted by the CDC in multiple sites within 14 of the 50 states in 2002. While Virginia was not included in the surveillance, the neighboring states of North Carolina and Maryland participated, and their rates were estimated at one out of 154 and one out of 149 children, respectively. Based on the CDC report, ASDs appear to affect children of different racial, ethnic, and socioeconomic backgrounds at similar rates. However, three groups of individuals have a greater likelihood of being affected. Males are four times as likely to be affected as females. Additionally, siblings of an individual diagnosed with an ASD are more likely to be affected. Finally, individuals who have certain genetic conditions, such as fragile X syndrome, are more likely to have an ASD than others.

While the CDC estimates are the best available prevalence rates, medical experts consulted by JLARC staff raised concerns that these estimates may be somewhat high. To determine ASD prevalence, CDC reviewed the medical and educational records of a sample of children residing within the 14 surveillance sites. Children were classified as having an ASD if either (1) they had a documented ASD diagnosis, or (2) their educational or medical records indicated unusual social behaviors consistent with ASDs. Depending on the surveillance site, between 14 and 43 percent of the children who were classified as having an ASD in the CDC estimate did not have a formal ASD diagnosis, but rather displayed ASD-like behaviors based on written records. CDC acknowledges in its study that these cases may have the greatest potential for false-positive classification. Despite this potential methodological issue with CDC's ASD prevalence estimate, it may be accurate for Virginia. According to data from the Virginia Department of Education (DOE), approximately one out of every 150 eight-year-olds enrolled in Virginia public schools in 2007 had been classified with an ASD and receives special education services for those disorders.

Historical Trends of ASD Prevalence

According to the CDC, the prevalence rate of ASDs has increased dramatically over the past ten years, rising from one out of every 2,500 children to one in 150 as of 2007. In Virginia, DOE has reported an increase of more than 400 percent in students with ASDs between 1998 and 2006. Although the dramatic increase in prevalence of ASDs is striking, the cause of this phenomenon is unclear. Three main theories have been developed to explain it, and while some evidence supports each of them, scientists have not yet determined how each theory influences the prevalence of ASDs. In fact, it appears that each of the three theories contributes to the increasing number of individuals diagnosed with ASDs.

The first theory posits that "diagnostic substitution" has taken place, whereby individuals who would have received a mental retardation or learning disability diagnosis in years past would now be diagnosed with an ASD due to increased awareness of the condition among clinicians and the public, better diagnostic tools, and the recognition that ASDs can be associated with other conditions (such as intellectual disabilities). A 2006 study found that the increase in the prevalence of ASDs between 1994 and 2003 was associated with a decline in the prevalence of mental retardation and learning disabilities. However, the study cautions that diagnostic substitution is likely only a partial explanation for the increased prevalence of ASDs.

A second theory posits that changes in diagnostic criteria and the inclusion of milder cases in the autism spectrum have led to the prevalence increase. Specifically, there was a move towards considering autism as part of a spectrum of disorders in the late 1980s, culminating in today's medical definition of ASDs which includes Asperger's syndrome and PDD-NOS. A recently published study found that while the incidence of ASDs rose seven- to eight-fold in California between the early 1990s and the present, approximately half of that increase could be explained by changes in the diagnostic criteria and inclusion of milder cases.

Finally, the third theory is that the prevalence of ASDs is truly increasing, suggesting that the cause(s) of ASDs (whether genetic, environmental, or both) is affecting people to a greater degree today. The California study supports this theory because 25 to 50 percent of the increase in ASD prevalence could not be explained by changes in diagnostic criteria or the inclusion of milder cases. In contrast, the first two theories would indicate that the same number of people had ASDs in the past as today, but that professionals were historically either mislabeling or not labeling individuals.

Future Trends in ASD Prevalence

Whether ASDs truly affect a larger number of people has tremendous policy ramifications in terms of the public resources that will be needed to support them in the future. However, without a clear explanation for why the prevalence of ASDs has increased so dramatically in recent years, predicting future prevalence trends is not possible. If diagnostic substitution explains much of the increase in ASD prevalence, then the prevalence rate should plateau. Conversely, if changes in environmental factors explain the increase, then the prevalence of ASDs may continue to increase until exposure to that environmental factor is reduced or eliminated. Determining what factors are causing ASDs is, therefore, critical to understanding future prevalence trends and their impact on public resources.

HOW ARE AUTISM SPECTRUM DISORDERS MANAGED?

Because the range and severity of impairments vary widely across the ASD spectrum, an array of interventions exists to alter behavior or develop new skills. In addition, medication may sometimes be used to manage symptoms related to ASDs. Moreover, some alternative therapies exist although experts are concerned with the lack of evidence supporting their effectiveness and, in some cases, the possibility that they may be harmful.

Array of Interventions Helps Individuals Improve Functional Levels

Individuals with ASDs can receive an array of services that are both specific to their condition as well as more generally used for persons with disabilities (Table 2). The National Institute of Mental Health states that ASD-specific psychosocial and behavioral interventions are important components of treating individuals with ASDs. Some of the most commonly used approaches include applied behavioral analysis (ABA) and Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), which are comprehensive programs designed to address the core deficits of ASDs.

Some of the most frequently used general interventions include speech, occupational, and physical therapy. These therapies help individuals with ASDs improve their ability to communicate and interact with others effectively, execute daily tasks such as personal care, build motor control, and improve posture and balance. In addition, positive behavioral supports (PBS) are often used to prevent problem behaviors by teaching alternative and appropriate behaviors.

Medications Can Be Prescribed to Manage Symptoms of ASDs

No medication currently exists to cure or directly treat the central features of ASDs. However, medication can help reduce some of the symptoms as well as other behaviors or conditions that are common among individuals with these disorders. For example, medications can be prescribed to address conditions such as anxiety, depression, behavioral problems, seizures, inattention, or hyperactivity that are often experienced by individuals with ASDs.

Limited Evidence Supports the Use of Complementary or Alternative Treatments

Some parents and caregivers have used treatments that are not considered conventional by the medical community for treating or

Table 2: Common Interventions for Individuals With Autism Spectrum Disorders

Interventions Used for All Disabilities	Description of Intervention
Inclusion	▪ Teaching philosophy that individuals with disabilities benefit from receiving an education within a mainstream classroom, and that supports and accommodations should be provided to facilitate individuals' inclusion.
Occupational Therapy	▪ Introduces, improves, or maintains critical life skills such as grooming, toilet training, dressing, feeding, social skills, fine motor skills, and gross motor coordination.
Physical Therapy	▪ Focused on improving ability to develop basic motor skills, build muscle strength, and improve coordination and skills.
Positive Behavioral Supports	▪ Based on applied behavior analysis (ABA) used to address problem behaviors; strategies view all behaviors as functional and attempt to make changes to reduce problem behaviors.
Speech/Language Therapy	▪ Designed to help individuals develop verbal and/or non-verbal communication skills.
Visual Strategies	▪ Used to enhance individuals' organization, communication, and comprehension; visual supports can be objects, printed words, pictures, body language, or environmental clues.

Interventions Used for ASDs	Description of Intervention
ABA, Applied Behavior Analysis based therapy	▪ Uses positive reinforcement and data-driven planning to decrease behavioral issues in order to build communication, play, social, academic, self-care, work, and community living skills. ▪ Specific interventions may include discrete trial training, incidental teaching, pivotal response training, and verbal behavioral intervention.
Floortime, also known as Developmental, Individual Differences, Relationship-Based Approach (DIR)	▪ Focuses on replacing stereotypical behavior with new activities involving social interaction, communication, and other skills. ▪ Therapists and parents use a child's preferences and stereotyped behaviors in imitation to help the child develop interaction skills. For example, if the child spins around the room, the therapist or family member follows. Eventually, the child waits for the therapist or family member before spinning. The therapist or family member then introduces similar, more functional activities to help the child organize him or herself.
LEAP, Learning Experiences: An Alternate Program for Preschoolers and Parents	▪ Multifaceted program for young children with ASDs which includes an inclusive preschool classroom component and a behavioral skill training program for parents. ▪ Specific interventions are based on ABA and include peer-mediated instruction, incidental teaching, self-management training, and prompting strategies.
TEACCH, Treatment and Education of Autistic and Related Communication Handicapped Children, also known as Structured Teaching	▪ Special education ABA-based program that uses visual cues to enhance the physical, social, and communicating environment for children with ASDs to build receptiveness, understanding, organization, and independence. ▪ Individuals work in a highly structured environment which may include the physical organization of furniture, clearly delineated daily activity areas, picture-based schedules and work systems, and instructional clarity.

Source: Centers for Disease Control and Prevention, Autism Speaks, National Institute of Mental Health, and Virginia Department of Education, *Services Available for Individuals with Autism and Pervasive Developmental Disorders*, 2002.

managing symptoms of ASDs. Examples of complementary or alternative treatments that are frequently cited in the literature include dietary interventions such as gluten- or casein-free diets, homeopathy, injections of secretin (a digestive hormone), and energy therapies. The literature often characterizes these approaches as "controversial" and does not present scientific evidence indicating their effectiveness. Moreover, the literature indicates some therapies can result in harm. In fact, chelation therapy, a method for removing toxic metals such as mercury from the body, has resulted in the death of at least one person with an ASD.

Chapter 2

Autism Spectrum Disorders Can Be Effectively Treated, Producing Cost Savings

In Summary

Even though continued research about the effectiveness of treating autism spectrum disorders (ASDs) is still needed, several approaches for treating ASDs have been found to improve the outcomes of individuals with these disorders. In particular, studies indicate that most young children with ASDs who participate in intensive early intervention programs experience improvements, with almost half achieving normal levels of functioning. According to cost-benefit analyses, providing intensive treatment to young children with ASDs can significantly reduce costs for special education and other forms of public assistance, and savings are likely to accrue over the lifetime of these individuals. While many approaches have been categorized as effective for treating ASDs, research indicates that packaged programs with a predetermined curriculum appear to have more promising results than programs that rely on a more informal mix of interventions, even if some of the underlying interventions in the informal mix are considered effective.

The dramatic increase in the prevalence of ASDs over the last decade has brought considerable attention to the disorder and prompted extensive research into effective treatment options by both the medical and educational communities. While scientists have yet to find a cure for ASDs, treatment methods exist that meaningfully improve the outcomes of individuals with ASDs, especially if initiated at a young age. The largest body of research exists for interventions based on applied behavior analysis (ABA). ABA-based interventions are supported by approximately 30 years of research pointing to their effectiveness and have been accepted by much of the medical community as effective techniques for treating ASDs, along with several other interventions. Further, research indicates that treatment is beneficial for many and could result in long-term savings of public resources over these individuals' lifetimes.

SEVERAL INTERVENTIONS HAVE ATTAINED SCIENTIFICALLY BASED STATUS, AND OTHERS ARE DEEMED PROMISING

While research has found that interventions for individuals with ASDs have varying levels of effectiveness, four have reached scientifically based status, and a dozen others are supported by sufficient evidence to be considered promising (Figure 2). This analysis was performed by ASD experts who compiled the research on more than 30 interventions commonly provided to individuals with

Figure 2: Interventions Have Been Categorized Based on Evidence of Effectiveness

Category	**Scientifically Based Practices**	**Promising Practices**	**Practices with Limited Support**	**Not Recommended Practices**
Description	Significant and convincing empirical efficacy and support	Appear effective and useful	Not supported by sufficient objective evidence	Ineffective and potentially harmful
Interventions	• Applied Behavior Analysis • Discrete Trial Training • Pivotal Response Training • LEAP	• Social Stories • Sensory Integration • PECS • Cognitive Behavioral Modification • Augmentative Communication • Cognitive Learning Strategies • Play Oriented Strategies • TEACCH • Psychopharmacology • Incidental Teaching • Joint Action Routines • Social Decision Making	• Floortime • Cognitive Scripts • Auditory Integration Therapy • Pet/Music/Art Therapy • Relationship Development Intervention • Cartooning • Van Dijk Curriculum • Gentle Teaching • Son-Rise • Fast For Word • Power Cards • Special Diets • Megavitamin Therapy	• Facilitated Communication • Holding Therapy

Note: LEAP, Learning Experiences: An Alternative Program for Preschoolers and Parents; PECS, Picture Exchange Communication System; TEACCH, Treatment and Education of Autistic and Communication-Handicapped Children

Source: Simpson, R.L. (2005). "Evidence Based Practices and Students with ASDs." *Focus on Autism and Other Developmental Disabilities*. 20:3, pp 140-149.

ASDs, and categorized them based on the amount and quality of the research demonstrating their effectiveness. This assessment is used by the Virginia Department of Education (DOE) to guide school personnel about interventions considered to be "research-based."

Treatment outcomes were one of the criteria that experts used to categorize the interventions. Evaluations of ABA-based interventions and Learning Experiences: An Alternative Program for Preschoolers and Parents (LEAP) found that approximately half of participants were placed in general education classrooms after treatment. Although less evidence exists to support the effectiveness of the Treatment and Education of Autistic and Communication-Handicapped Children (TEACCH) program, an evaluation found that participants gained an average of 15 to 19 points in intelligence quotient (IQ) levels by nine years of age. In addition, limited research on the effectiveness of Floortime has been conducted, but one evaluation indicated that over half (58 percent) of children rated outside of the autism spectrum after being assessed at least two years after treatment began. While this approach appears to yield favorable outcomes, these results are from one study and have not been sufficiently validated to consider this practice "promising." In addition to considering outcomes, the ASD experts who classified the effectiveness of ASD interventions also based their assessment on the qualifications of persons implementing the

Evaluations of ABA-based interventions and the LEAP program found that approximately half of participants were placed in general education classrooms after treatment.

treatment, potential risks associated with implementing the treatment, and methods or instruments used to measure treatment outcomes.

Even though ASD experts conducted a comprehensive review, their categories of interventions should be interpreted with caution. First, the literature used was published prior to 2005, and more recent evaluations may have changed the evidence base for some interventions. In addition, interventions labeled as having limited support should not necessarily be interpreted as ineffective. Instead, this category simply indicates that research on these interventions has not been sufficiently rigorous to label them as promising or scientifically based. Furthermore, the fact that an intervention is labeled scientifically based does not preclude the need for further research. While ABA-based therapies are labeled as scientifically based and have over 30 years of supporting evidence including several randomized control trials (two of which are listed in Table 3), critics of these therapies recommend conducting further evaluations that incorporate larger and more representative sample sizes and rely on more consistent treatment methods.

INTENSIVE EARLY TREATMENT CAN SIGNIFICANTLY IMPROVE FUNCTIONING AND LOWER PUBLIC COSTS

Multiple research studies evaluating the effectiveness of treating children with ASDs have documented that most young children who receive intensive interventions experience improved functioning and require fewer supports over time. In addition, several studies have used these results to determine that the provision of intensive ASD interventions can yield significant savings as a result of a decreased need for special education and long-term care services.

ASD Treatment Can Improve Functioning

Early Intensive Behavioral Intervention (EIBI)

EIBI is generally characterized as 35 to 40 hours per week of ABA-based treatment which usually begins by age three and lasts approximately two to three years.

Research studies have found that most children who receive intensive behavioral interventions experience improvements. In particular, several studies have found that almost half of young children who received early intensive behavioral intervention (EIBI) reached normal or near-normal levels of functioning because they attained IQ levels in or above normal ranges (IQ score of 90 or higher), improved adaptive behaviors and verbal expressions, and successfully transitioned to general education classrooms without supports. Notably, EIBI appears to improve cognitive functions among some children with ASDs rather than simply preventing further declines. For example, early intervention has been found to prevent declines for some young children with Down syndrome, but they continue to exhibit mild or moderate developmental delays.

Table 3 summarizes the results of three major studies comparing outcomes between young children with ASDs who received EIBI (treatment group) and at least one group of similar children who received less intensive treatment (comparison group). These studies included children with autistic disorder or pervasive developmental disorder–not otherwise specified (PPD-NOS) and, as a result, the effectiveness of EIBI for individuals with Asperger's syndrome is largely unknown. In each study, children who received EIBI more frequently achieved IQ gains and placements in general education classroom settings than those receiving less intensive forms of treatment. In particular, results of a landmark 1987 study demonstrated approximately 90 percent of children with autism who received EIBI made improvements:

- 47 percent achieved normal or near-normal functioning and were successfully placed in general education classrooms;
- 42 percent achieved moderate gains in functioning, required decreased levels of care and assistance, and remained in special education classrooms though of lesser intensity; and
- 11 percent did not achieve gains, continued to require the same levels of assistance, and remained in intensive special education classrooms.

Most notably, children participating in the 1987 study were contacted for a follow-up study, and results indicated that approximately four years after ending treatment, children in the treatment group had maintained both their gains in IQ and placement in a general education classroom. Furthermore, a recent study (not included in Table 3) replicated the results of the landmark 1987 study and also found that nearly half (48 percent) of children attained normal functioning after treatment.

ASD Treatment Can Reduce Costs

Analyses conducted in two states found that providing EIBI treatment for three years could result in cost savings by reducing further special education costs for some children, and eliminating these costs altogether for others. Although intensive ASD treatment such as EIBI is costly, so is the provision of special education and related services to children with ASDs: costs for providing EIBI for one year are estimated to range from $23,000 to $60,000 (depending on the design of the treatment program), and are typically incurred for two to three years. In contrast, research suggests that most children with ASDs who do not receive intensive early

Table 3: Multiple Studies Demonstrate Children Who Receive Intensive Treatment Fare Better Than Those Who Receive Less Intensive Services

	Outcomes	
Group	**Average Change in IQ Points**	**Educational Placement**
EIBI compared to less intensive public school special education (2006 study)		
Treatment	+25	▪ 29% in general class without supports ▪ 52% in general class with supports
Comparison	+14	▪ 5% in general class
EIBI compared to less intensive parent-training model (2000 study)		
Treatment	+16	▪ 27% in general class without supports
Comparison	-1	▪ No children in general class without supports
EIBI compared to less intensive treatment (1987 study)		
Treatment	▪ 47% achieved IQ in normal range (94-120)	▪ 47% in general class without supports ▪ 42% in less intensive special education class for language delayed ▪ 11% in intensive special education class for children with autism or intellectual disability (ID)
Comparison	▪ 2% achieved IQ in normal range	▪ 2% in general class without supports ▪ 45% in less intensive special education class for language delayed ▪ 53% in intensive special education class for children with autism or ID

Note: A more detailed table on the results of these studies can be found in Appendix C.

Source: JLARC staff review of literature on early intensive behavioral interventions.

interventions are likely to remain in an intensive special education classroom up to age 22 at an average cost that will vary by state but was $21,450 in Virginia in FY 2008. Two studies used results from the 1987 study (Table 3) to estimate the percentage of students receiving treatment who would achieve normal functioning or require fewer supports.

A study published in a national journal found that Pennsylvania could save an average of $187,000 to $203,000 on each child who received three years of EIBI relative to one who received special education services until age 22. The Pennsylvania study also suggested that cost savings would likely continue to accrue after children exit the school system. The study found that the state could save from $656,000 to $1.1 million per child if expenditures up to age 55 are included. Another study published in a national journal found that Texas could save an average of $208,500 in education costs for each student who received three years of EIBI relative to a student who received 18 years of special education from ages four to 22. Applied to the estimated 10,000 children with ASDs in Texas, it was estimated that the state could save almost $2.1 billion by implementing intensive treatment programs.

By applying the methodology used in the Pennsylvania and Texas studies to Virginia-related data, JLARC staff estimate that the Commonwealth could save approximately $137,400 in special education costs per student with an ASD if EIBI was consistently provided. In fact, the analysis indicates that Virginia could realize savings as long as at least 42 percent of students with ASDs who received EIBI make moderate improvements (require less intensive services and fewer supports), which is a substantially more conservative outcome than the outcomes reported in the research literature.

TREATMENT PACKAGES APPEAR MORE EFFECTIVE THAN MIXED-METHOD MODELS

Studies have found that interventions relying on a comprehensive pre-determined set of strategies (or "packages") were generally more effective in treating individuals with ASDs than a more informal mix of strategies (or "mixed-method"). While mixed-method strategies often include the same components as packages (such as the use of visuals or play therapy), they generally rely on individual providers to choose which components to use, how frequently, and in what sequence. Instead, packages such as ABA, LEAP, or TEACCH prescribe a curriculum that is individualized but relies on a consistent framework.

Applied Behavior Analysis (ABA)

ABA is the specific and comprehensive use of principles of learning, including operant and respondent learning, in order to address behavioral needs of widely varying individuals in diverse settings. While ABA itself is not a package, several curricula for providing therapies based on ABA have been developed.

Thus far, mixed-method treatment has been compared only to ABA-based programs that use the same strategies as the 1987 study (Table 3), but an evaluation comparing LEAP and TEACCH to mixed-method treatment is currently underway. Two studies comparing intensive ABA-based programs to mixed-method treatment found that increases in IQ were significantly larger for those receiving ABA-based treatment, on average (Table 4). In one of these studies, children who received ABA-based treatment experienced a 30-point gain in IQ scores (on average) compared to an eight-point gain in IQ by those who received mixed-method treatment. In addition, over half of the children who received ABA-based treatment had IQ scores in the normal range after treatment compared to only 16 percent of those who received mixed-method treatment. The last study listed in Table 6 compared low intensity ABA-based treatment with mixed-method treatment, and results demonstrated that mixed-method treatment was ineffective since children who received this form of treatment lost almost three IQ points compared to an eight-point gain by those receiving ABA-based treatment, on average.

Because mixed-method programs often include the same strategies as packaged programs, they could theoretically be just as effective. However, several potential problems with the implementation of mixed-method treatment have been cited in the literature. First, mixed-method programs may use interventions that are not scientifically based or are not compatible with each other. According to the literature, providers need to have a full understanding of each intervention's underlying assumptions so that the interventions used are not working at cross-purposes. In practice, providers may lack the knowledge to successfully make this assessment. In addition, the use of multiple interventions may be confusing to children with ASDs if they are not implemented in a systematic way, particularly because these children often do not respond well to changes in routine. One study noted that the typical day for children receiving mixed-method treatment involved multiple transitions from one intervention to the next with a good deal of variation in the way each intervention was provided.

Table 4: Children Participating in ABA-Based Programs Achieved Larger Gains in IQ Than Those in Mixed-Method Programs

Group	Description	Average Change in IQ Points
Intensive ABA-based therapy for young children compared to intensive mixed-method treatment (2005 study)		
Treatment	29 children who received 25-40 hours per week of ABA-based therapy	+30
Comparison	16 children who received an average of 25-30 hours per week of mixed interventions	+8
Intensive ABA-based therapy compared to intensive mixed-method treatment in an elementary school setting (2002 study)		
Treatment	13 children who received an average of 29 hours per week of ABA-based therapy	+17
Comparison	12 children who received an average of 29 hours per week of mixed interventions	+4
Low intensity ABA-based therapy compared to mixed-method treatment (2006 study)		
Treatment	13 children who received 12 hours per week of ABA-based therapy	+8
Comparison	15 children who received 12 hours per week of mixed-method treatment	-3

Source: JLARC staff review of literature on early intensive behavioral interventions.

Chapter 3

Current Service Delivery System for Virginians With Autism Spectrum Disorders

In Summary

Virginia operates several publicly supported programs to help diagnose, treat, and manage autism spectrum disorders (ASDs) through various agencies. Young children can receive services through the State's Early Intervention program, while school-age Virginians are entitled to supports and services necessary for an appropriate education that can ultimately lead to independence. Medicaid-funded waiver programs also offer supports to eligible persons with developmental disabilities of all ages. Beyond waivers, services available to adults with ASDs are limited primarily to employment supports and vocational training. Although the Department of Behavioral Health and Developmental Services will become the lead agency for developmental disabilities in July 2009, no State entity has previously been responsible for coordinating the complex array of programs and agencies that serve individuals with ASDs. While they represent a valuable resource for eligible individuals, existing programs do not constitute a comprehensive system of care that fully meets the needs of all individuals with ASDs. Many Virginia families report supplementing publicly supported programs, but their personal resources are often insufficient to pay for extensive and lifelong services, and health insurance policies do not appear to consistently or comprehensively cover ASD-related therapies.

Individuals with ASDs and their families need access to an array of services to diagnose, treat, and manage their condition. In Virginia, several publicly supported programs serve individuals with ASDs at different life stages. However, the existence of multiple programs should not be interpreted to mean that the needs of all Virginians with ASDs are fully met. Some Virginians cannot obtain the full array of services needed because they fail to meet eligibility criteria, have particularly severe needs, or seek assistance from programs with limited funding. Further, few processes exist to coordinate the complex network of existing programs and link Virginia families with needed resources.

Individuals with ASDs must often obtain services from private providers to supplement publicly supported programs, but their personal resources are not always sufficient to secure needed care. Consequently, some Virginians with ASDs and their families are not receiving the entire array of services required to fully meet their needs. The issues that preclude publicly supported programs from fully addressing the needs of persons with ASDs as well as potential solutions that the State could explore to alleviate these gaps are discussed in Chapters 4 through 8.

PUBLIC PROGRAMS SUPPORTING VIRGINIANS WITH ASDs

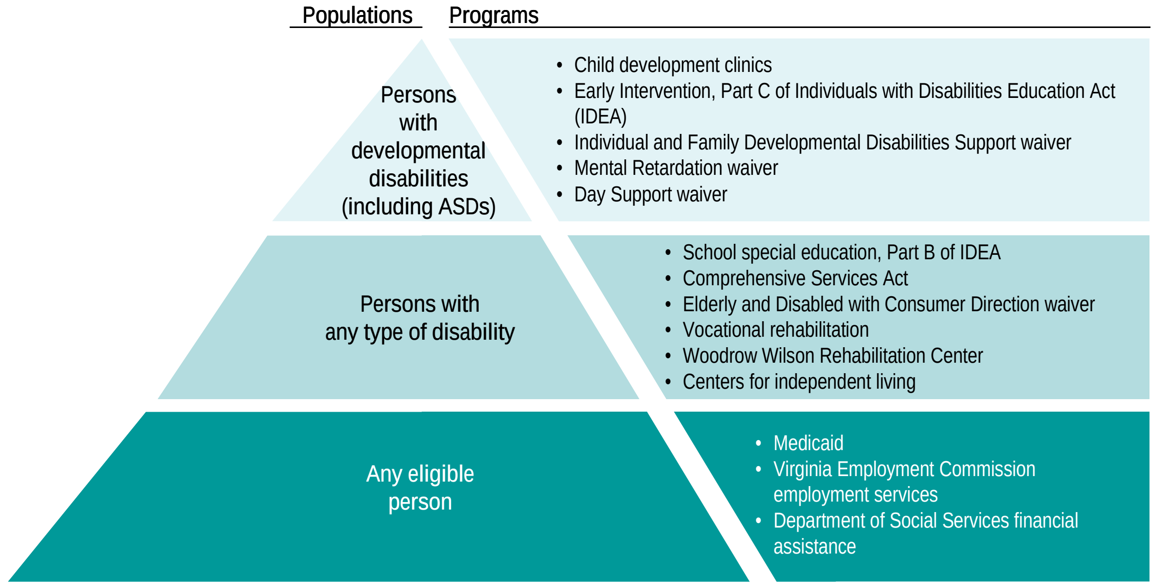
Several programs serve persons with ASDs in Virginia. While individuals with ASDs can access many publicly supported services, this study focused only on programs designed specifically for persons with disabilities. These programs are administered by several agencies that address many service needs and are funded by a mix of federal, State, and local sources.

Scope of Programs Examined in Study

This study focused primarily on publicly supported programs that target individuals with disabilities. Individuals with ASDs can access an array of programs that target three different and sometimes overlapping populations: (1) individuals with developmental disabilities, including ASDs; (2) Virginians with disabilities of any type; and (3) persons who meet eligibility criteria not related to disabilities (Figure 3).

For purposes of this report, programs that are available to eligible Virginians regardless of their disability status were not examined because they do not address ASD-specific needs, and resolving issues affecting these programs would require solutions that extend beyond the scope of this study. Instead, this review focused on programs that serve primarily individuals with disabilities, including ASDs, because they are designed to recognize and address the specific challenges encountered by these individuals.

Figure 3: Target Populations of Publicly Supported Programs Available to Virginians With ASDs



Source: JLARC staff interviews with agency personnel and review of program documentation.

Overview of Major Publicly Supported Programs Serving Virginians With ASDs

Virginians with ASDs and their families can receive services from several programs administered by a variety of State human services agencies and the Department of Education. Collectively, the programs listed in Table 5 provide services to diagnose, treat, and manage ASDs, as well as support adults in achieving some measure of independence and productivity. A snapshot of the scope of each program is presented in Figure 4, and more detailed descriptions are available in Appendix D.

Table 5: Major Publicly Supported Programs Serving Virginians With ASDs

Department / Office	Program	Description of Services Provided
Health	Child Development Clinics	Multidisciplinary diagnostic services for children suspected of having developmental or behavioral disorders.
Medical Assistance Services	Individual and Family Developmental Disabilities (DD) Support Waiver	Home and community-based care for individuals with developmental disabilities age 6 or over who would otherwise require placement in an intermediate care facility for persons with mental retardation (ICF/MR).
	Elderly or Disabled with Consumer Direction (EDCD) Waiver	Home and community-based services for individuals who would otherwise require placement in a nursing facility.
Behavioral Health and Developmental Services	Mental Retardation (MR) Waiver	Home and community-based care for individuals with mental retardation (or developmental disabilities if under age 6) who would otherwise require placement in an ICF/MR facility.
	Day Support Waiver	Training, assistance, and specialized supervision for individuals with mental retardation (or developmental disabilities if under age 6) who would otherwise require placement in an ICF/MR facility.
	Early Intervention, Part C of the Individuals With Disabilities Education Act (IDEA)	Supports and services for children with or at-risk of developmental disabilities to increase their participation in family and community activities by coaching parents and caregivers.
Education	School Special Education, Part B of IDEA	Supports and services appropriate to meet the unique needs of students with disabilities and prepare them for further education, employment, and independent living.
Comprehensive Services	Comprehensive Services Act (CSA)	Community-based and family focused services for children with emotional or behavioral problems requiring cross-agency involvement.
Rehabilitation Services	Vocational Rehabilitation	Job coaching and supported employment services for individuals with disabilities to find and maintain competitive employment.
	Woodrow Wilson Rehabilitation Center	Campus-based vocational and life skills training for transition-age school students and adults with disabilities.
	Centers for Independent Living (CILs)	Services and advocacy to promote the independence of people with disabilities through services such as information and referral, advocacy, peer counseling, and independent living skills training.

Source: JLARC staff interviews with agency personnel and review of program documentation.

Figure 4: Key Operational Characteristics of Major Publicly Supported Programs Serving Virginians With ASDs

		Child Development Clinics	Early Intervention Part C	School Part B	Comprehensive Services Act	Mental Retardation Waiver	Day Support Waiver	DD Waiver	EDCD Waiver	DRS Vocational Rehab.	Woodrow Wilson Rehabilitation Center	Centers for Independent Living
Eligibility Criteria												
Age	0-5	✓	✓(to 3)	✓ (2-5)	✓	✓	✓	✗	✓	✗	✗	✗
	6-21	✓	✗	✓	✓	✓	✓	✓	✓	✓(16-21)	✓(16-21)	✓(16-21)
	22+	✗	✗	✗	✗	✓	✓	✓	✓	✓	✓	✓
Any Income Level		✓	✓	✓	✓	✗	✗	✗	✗	✓	✓	✓
Any Level of Functioning		✓	✓	✓	✓	✗	✗	✗	✗	✓	✓	✓
Program Resources												
Unlimited Funding		✗	✗	✓	✓	✓	✓	✓	✓	✗	✗	✗
Unlimited Slots		✓	✓	✓	✓	✗	✗	✗	✓	✓	✓	✓
Settings Targeted												
School		n/a	n/a	✓	✓	✓	✗	✓	✗	✓	✗	✗
Home and Community		n/a	✓	✗	✓	✓	✓	✓	✓	✗	✓	✓
Employment		n/a	n/a	✓	✗	✓	✓	✓	✓	✓	✓	✓
Types of Services Available												
Screening / Diagnosis		✓	✓	✓	✓	✗	✗	✗	✗	✗	✗	✗
Case Management		✓ (6 months)	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓
Individual Services		✗	✓	✓	✓	✓	✓	✓	✓	✗	✗	✗
Family Services		✗	✓	Varies	✓	✓	✓	✓	✓	✗	✗	✗
Community Supports		✗	n/a	✗	✓	✓	✓	✓	✓	✗	✗	✓
Employment Services		✗	n/a	Varies	✗	✓	✓	✓	✗	✓	✓	✓

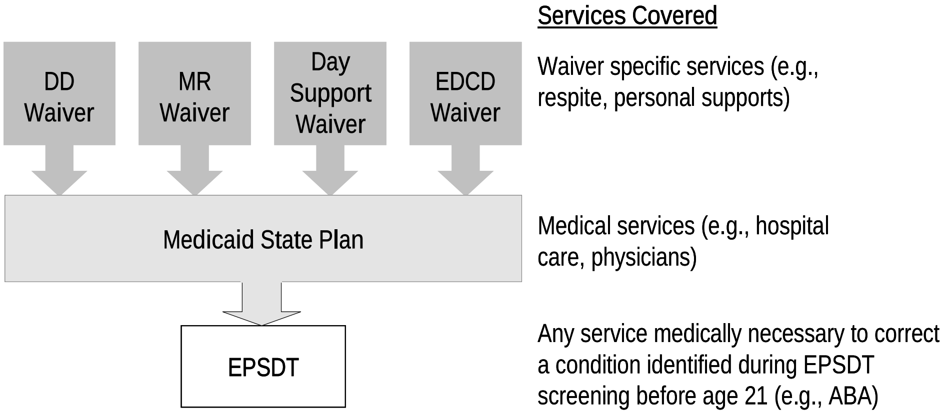
✓Available ✗Not available n/a Does not apply

Source: JLARC staff interviews with agency personnel and review of program documentation.

The Department of Health operates nine child development clinics that provide multidisciplinary assessments and diagnoses of children with developmental disabilities. In addition, Virginia operates four Medicaid waiver programs that serve as alternatives to institutionalization for people with developmental disabilities for as long as services are needed. Waiver services can be especially important for adults, for whom no other entitlement programs are available. Individuals who are enrolled in any waiver program also become automatically eligible for the Medicaid State plan, which offers certain services not directly available through waivers, such as medical care. In addition, children under age 21 who are enrolled in the Medicaid State plan are entitled to receive any service identified as medically necessary through the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program, even if those services are not covered by the State plan or waivers (Figure 5). Such services could include interventions based on applied behavioral analysis (ABA).

Children under age 21 who are enrolled in the Medicaid State plan are entitled to receive any service identified as medically necessary through EPSDT, even if those services are not covered by the State plan.

Figure 5: Waiver Recipients Can Access Additional Medicaid-Funded Services Through State Plan and EPSDT



Source: JLARC staff interviews with agency personnel and review of program documentation.

The Department of Medical Assistance Services has administrative authority over all waivers, but oversees the daily operations of only two. The Individual and Family Developmental Disabilities Support (DD) waiver offers a comprehensive array of supports and services to individuals age six or older who have developmental disabilities (including ASDs) but no co-occurring intellectual disability. The Elderly or Disabled with Consumer Direction (EDCD) waiver offers a more limited range of services to eligible individuals of all ages and is sometimes used by individuals waiting to be enrolled in more comprehensive waiver programs.

Agency Name Change

On July 1, 2009, Virginia's Department of Mental Health, Mental Retardation and Substance Abuse Services will be renamed the "Department of Behavioral Health and Developmental Services."

The Department of Behavioral Health and Developmental Services (BHDS, formerly Mental Health, Mental Retardation and Substance Abuse Services) oversees the daily operations of the remaining two waivers. The Mental Retardation (MR) waiver offers a comprehensive range of services designed to meet the needs of Virginians with intellectual disabilities (some of whom may have a co-occurring ASD diagnosis) as well as children under the age of six who have a developmental disability. The Day Support waiver is a companion to the MR waiver which offers a more limited array of services and is generally used by individuals who are waiting to receive services through the MR waiver. In addition to the two waivers, BHDS also administers Part C of the federal Individuals with Disabilities Act (IDEA), which provides early intervention services primarily by coaching the caregivers of children under age three with a developmental delay.

Schools administer Part B of IDEA, which provides special education and related services to children ages two through 21 who have a disability that negatively impacts their access to the general curriculum. By law, schools must serve children in the least restrictive environment and provide individualized services needed to receive an educational benefit and ultimately achieve further education, employment, and independent living. Children with ASDs who are enrolled in the School Part B program may also, in some cases, receive services through the Comprehensive Services Act (CSA), which serves children with behavioral and emotional issues that require cross-agency collaboration. In particular, CSA is responsible for paying the cost of day schools and other day services needed to afford students with ASDs an appropriate education.

The Department of Rehabilitative Services (DRS) administers programs that aim to enable adults with disabilities to find and maintain employment, and assist youths in transitioning from school to work. Individuals can also receive a range of vocational training and life skills at the Woodrow Wilson Rehabilitation Center, located near Staunton. In addition, Centers for Independent Living provide services to reduce barriers to independence for adults with disabilities.

Key Financial Characteristics of Major Publicly Supported Programs Serving Virginians With ASDs

By far, the Part B program offered in public schools is the largest program in terms of budget and caseload for individuals with ASDs.

All programs that support individuals with ASDs also serve persons with other types of disabilities. In fact, individuals with ASDs account for less than 12 percent of the caseload of most programs, with the exception of the DD waiver where they comprise nearly 60 percent of all cases (Table 6). By far, the Part B program offered

Table 6: Clients and Funding Sources of Major Publicly Supported Programs Serving Virginians With ASDs (FY 2008)

Program	Clients with ASDs		All Clients					
	Number Served	Spending ($M)	Number Served	Spending ($M)	Funding Sources			
					Federal %	State %	Local %	Other[d] %
School Part B	7,580	$152.3	169,538	$2,024.0	13	23	64	-
Mental Retardation Waiver	837	$46.9	7,295	$430.0	50	50	-	-
Comprehensive Services Act	831	$36.1	18,195	$380.5	-	64	36	-
Vocational Rehabilitation	794	$0.5 [b]	25,105	$72.8 [c]	80	20	-	-
Early Intervention Part C	460 [a]	--	11,351	$32.5	39	22	26	13
Elderly or Disabled with Consumer Direction Waiver	371	$1.6	16,159	$227.9	50	50	-	-
Individual and Family Developmental Disabilities Support Waiver	316	$3.4	541	$10.6	50	50	-	-
Woodrow Wilson Rehab. Center	123	$1.0	2,484	$24.5	57	35	-	8
Day Support Waiver	33	$0.3	270	$3.1	50	50	-	-
Centers for Independent Living	--	--	8,500	$7.7	19	68	13	-
Child Development Clinic	--	--	2,516	$3.6	54	46	-	0
TOTAL	--	--	261,954	$3,217.1	21	34	45	0

Note: --, Information not available.
[a] Includes children with ASDs or suspected ASDs, but not all children with ASDs have been identified by age three.
[b] Excludes funding for Long-Term Employment Supports and Services (LTESS).
[c] Includes funding for LTESS.
[d] Includes primarily client fees.

Source: JLARC staff interviews with State agency personnel and analysis of financial data supplied by agencies.

in public schools is the largest in terms of budget and caseload for individuals with ASDs. Publicly supported programs that serve Virginians with ASDs are funded through a combination of sources, which consistently includes federal and State funding (Table 6). The federal government grants Virginia funding through multiple statutes:

- The Individuals with Disabilities Education Act, which supports the Early Intervention Part C and School Part B programs for children with disabilities;
- The Vocational Rehabilitation Act, which provides for vocational rehabilitation, supported employment, independent living, and client assistance for individuals with disabilities;
- Title V of the Social Security Act, which aims to improve the health of mothers and children, including those with special health care needs; and
- Section 1915(c) of the Social Security Act, which authorizes the Medicaid program to create waiver programs as alternatives to institutionalization.

In order to receive federal funds through any of these programs, states are required to match a portion of the federal funds allocated. Virginia has appropriated sufficient general funds to meet federal matching requirements, and in some cases has contributed additional State-only funds. For example, the State operates CSA to serve children with behavioral and emotional disturbances as well as the Long-Term Employment and Support Services (LTESS) program for individuals with significant disabilities who require extended assistance to remain employed.

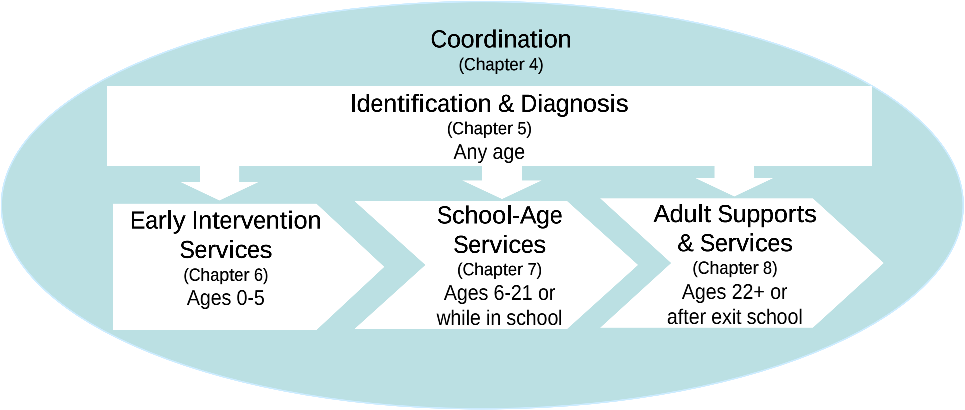
While local funds are used less frequently, they are the primary funding source of the Part B program administered in schools. Because the School Part B program serves the largest number of Virginians with ASDs and incurs the greatest expenditures for this population (Table 6), localities are a critical funding source for serving Virginians with ASDs. A formula determines the minimum level of funding required from each locality, but localities can exceed this requirement, given available resources. CSA also requires a local match, and some local governments choose to fund the Early Intervention Part C program and CILs. Other funding sources support a few programs, generally through client fees.

Service Delivery Framework Comprised of Four Components

Because ASDs are generally lifelong disabilities and the needs of individuals with ASDs and their families change over time, a service delivery system that is comprehensive would address all life stages. These stages can be broken out into four components (Figure 6). Issues related to each component and how well they are coordinated are discussed in greater detail in Chapters 4 through 8 of this report.

Prior to accessing services, the possibility of an ASD must first be identified, and an assessment can then be conducted to establish a formal ASD diagnosis. ASDs are currently diagnosed at all life stages. While a diagnosis often can be made in children between ages two and three, certain disorders such as Asperger’s syndrome may not be recognized until children enter school. Further, individuals who grew up before there was as much ASD awareness are still commonly diagnosed as adults. After individuals have either been identified with a developmental delay or diagnosed with an ASD, they can begin receiving early intervention services until age five, transition to school-age services until they exit the school system or reach the age of 21, and secure adult supports and services once they reach age 22 or have exited the school system.

Figure 6: Components of Service Delivery System for Virginians With ASDs Correspond to Life Stages and Report Chapters



Source: JLARC staff interviews with agency personnel and review of program documentation.

Table 7 illustrates how Virginia programs that comprise the State's service delivery system for individuals with ASDs can be broken out into these four major components. No single program addresses the needs of individuals with ASDs through all life stages. Consequently, Virginians with ASDs often transition between multiple programs during their lifetime. Within each life stage, several programs exist to serve individuals with ASDs. However, the programs are generally not duplicative because they have different eligibility criteria, arrays of services, and funding constraints that limit which individuals can participate. Still, eligible Virginians may be enrolled in multiple programs that complement one another. For example, a child could receive educational services through their school's Part B program as well as additional therapeutic services through a Medicaid waiver.

Table 7: Major Components of Service Delivery Framework Addressed by Publicly Supported Programs in Virginia

Program	Identification and Diagnosis	Early Intervention	School-Age Services	Adult Supports and Services
Child Development Clinic	✓			
Early Intervention Part C	✓	✓		
School Part B	✓	✓	✓	
CSA		✓	✓	
EDCD Waiver		✓	✓	✓
MR Waiver		✓	✓	✓
Day Support Waiver		✓	✓	✓
DD Waiver			✓	✓
Vocational Rehabilitation			✓	✓
Woodrow Wilson Rehabilitation Center			✓	✓
Centers for Independent Living			✓	✓

Source: JLARC staff interviews with agency personnel and review of agency documentation.

OVERVIEW OF COORDINATION EFFORTS

Several initiatives have been undertaken to coordinate the delivery of services to Virginians with disabilities. In July 2009, the Department of Behavioral Health and Developmental Services will begin acting as lead agency for coordinating services addressing developmental disabilities. Although prior to that point no State entity has been responsible for building a system of care for persons with developmental disabilities, several councils and organizations have been created to conduct strategic planning and identify major gaps in services. Yet, their efforts generally do not focus on ASDs exclusively. In addition, information and referral support has been made available to all Virginians with disabilities. Finally, case managers are often available to link individuals with ASDs to available programs and services.

Coordinating Service Delivery Across Agencies

To date, few State entities have been responsible for coordinating services specifically for Virginians with ASDs. However, the Department of Behavioral Health and Developmental Services (BHDS) will assume this responsibility as of July 1, 2009. Still, most existing councils and organizations focus on all disabilities, rather than strictly ASDs.

No State-level entity has been responsible for coordinating the multiple programs and agencies that serve Virginians with ASDs.

Agency Oversight and Planning for ASDs and Developmental Disabilities. Prior to 2009, no State-level entity has been responsible for coordinating the multiple programs and agencies that serve Virginians with ASDs. Each agency listed in Table 5 has traditionally overseen the delivery of services and development of public policy strictly as they relate to their target population, but no entity has been tasked with considering the broader system of care formed by existing programs. While Virginia and many other states have focused historically on intellectual disabilities, there has been a national shift toward overseeing all developmental disabilities through one entity. In fact, Alabama will soon be the only state that remains without an agency responsible for all developmental disabilities.

On July 1, 2009, BHDS will assume responsibility for overseeing the delivery of services to individuals with all types of developmental disabilities, including ASDs. This positive step was initiated by the Secretary of Health and Human Resources and enacted by the 2009 General Assembly at the request of ASD stakeholders who saw the need for greater State-level coordination. In addition to renaming the agency, this shift will initially entail hiring two individuals with expertise in developmental disabilities and/or ASDs, and starting to implement the action plan designed by an advisory committee in August 2008.

At present, the department plans to add these two new positions to its existing division of intellectual disabilities, which will be renamed to reflect its broader purpose. While these two positions will have lead responsibility for developmental disabilities other than intellectual disabilities, they will be able to draw from the expertise of other division staff who are already well-versed in overseeing a service delivery system.

While designating a lead agency for developmental disability services will greatly improve the State's ability to coordinate its programs, there were initial disagreements over which entity should be assigned responsibility for ASDs, and whether this entity should oversee all developmental disabilities (including intellectual disabilities) or solely ASDs. In 2007, the Joint Commission on Health Care convened an advisory committee which identified BHDS as the most suitable lead agency for overseeing all developmental disabilities. However, the ASD community voiced strong concerns over the feasibility of restructuring BHDS in a way that would appropriately serve this new population, and the time that would be required to achieve this new structure. As a result, the advisory committee ultimately requested the Secretary of Health and Human Resources to further examine the issue. The second advisory committee appointed by the secretary acknowledged that there was no obvious choice, but also selected BHDS as lead agency for all developmental disabilities.

Advisory Councils and Commissions. Virginia does not have an advisory council that focuses strictly on ASDs. The Virginia Board for People with Disabilities serves as the State's planning council regarding all developmental disabilities, as required by State and federal law. The board is comprised of 40 members, including 24 individuals with disabilities and family members, and nine representatives from agencies involved in the delivery of services to Virginians with developmental disabilities. One of the primary functions of the board is to "advise the Governor, legislators, and agencies on public policy issues as well as on how to develop programs and services for people with developmental disabilities that will eliminate barriers to full inclusion in all facets of community life." In addition, the Board engages in advocacy, capacity building, and system transformation activities to support a coordinated service delivery system that is centered around and directed by consumers and their families, and enables individuals with developmental disabilities to be independent, productive, and included in all facets of community life.

In addition to a planning council that focuses on developmental disabilities, Virginia also has a Disability Commission. Formed in 1990, the commission is comprised of 12 legislative and citizen members who advance budget proposals and address policy issues aiming to maximize the self-sufficiency of Virginians with physical and sensory disabilities.

Statewide Entities Supporting Service Delivery for Individuals With ASDs. Virginia relies upon several entities to continually improve the delivery of services to individuals with ASDs, including the Virginia Autism Council (VAC), Commonwealth Autism Service, and the Partnership for People with Disabilities. The Virginia Autism Council was established in 2001 at the recommendation of the Disability Commission in order to advance higher education, training, and educational opportunities for personnel and caregivers supporting individuals with ASDs. VAC's membership is comprised of 20 autism experts from State and local agencies, universities, nonprofit organizations, and advocacy groups. The council has defined skills competencies needed to guide the development of professionals and paraprofessionals who serve individuals with ASDs, and continues to advertise available training opportunities as well as work with Virginia universities to offer ASD-specific coursework. The council is not a formal State entity recognized in the *Code of Virginia*.

Commonwealth Autism Service (CAS) is a nonprofit organization partially funded by the State, which aims to achieve a coordinated service delivery system for Virginians with ASDs and their families. CAS was formed in 1995 by parents of individuals with ASDs, and now employs more than 20 staff in several Virginia locations. To realize its vision, CAS works with a broad array of ASD stakeholders and provides information and referrals, consultative services for individuals with ASDs, workshops for family members, training on research-based strategies to professionals, support for local coordination, and assessment services in partnership with the Virginia Commonwealth University (VCU) Medical Center.

The Partnership for People with Disabilities is affiliated with VCU's School of Education and is recognized by the federal government as Virginia's center of excellence in developmental disabilities. Founded in 1985, the partnership is staffed by professionals and students who support individuals with developmental disabilities and their families. Their efforts are targeted at individuals with disabilities through all life stages, and focus specifically on early intervention, educational services and supports, and adults and aging persons.

Coordinating Information About Available Programs, Services, and Providers

There are numerous sources of information about community services and programs, although none is comprehensive and focuses exclusively on individuals with ASDs. Commonwealth Autism Service offers an information and referral service specifically for individuals with ASDs and their families. The State's primary directory of community services, 2-1-1 Virginia, is a statewide service of the Department of Social Services that can be accessed both by phone and through the Internet. Individuals who call 2-1-1 are assisted by trained professionals who can direct them toward services and providers who meet their individual needs. To better address the specific needs of individuals with disabilities, 2-1-1 Virginia also supports the Virginia Easy Access website, which currently focuses only on services for adults. The websites of national and local ASD advocacy groups also frequently offer a list of providers with expertise in ASDs. In addition, families of children with ASDs can obtain information about the special education system through parent resource centers available in 53 school divisions, although the scope of each center varies greatly by division.

Coordinating Individual Care Through Case Management

Because individuals with ASDs and their families often have multifaceted needs that may be met by a variety of programs and agencies, case management can be an important tool in ensuring the efficient and effective provision of services. Many publicly supported programs that serve individuals with ASDs offer case management services and create plans of care, with the exception of the Elderly or Disabled with Consumer Direction (EDCD) waiver.

PRIVATELY FUNDED SERVICES FOR INDIVIDUALS WITH ASDs

When publicly supported services are either unavailable or insufficient to meet their needs, individuals with ASDs and their families may secure services at their own expense through private providers. The two primary financing options for these services are (1) personal resources, and (2) health insurance coverage. However, the personal resources of many families may be insufficient to pay for extensive and lifelong services, and health insurance policies do not appear to consistently or comprehensively cover ASD-related therapies.

Using Personal Resources to Fund Services

The vast majority (84 percent) of Virginians with ASDs and their families reported pursuing privately funded services.

The vast majority (84 percent) of Virginians with ASDs and their families reported pursuing privately funded services, according to a JLARC staff survey. Of those, slightly more than half were able to obtain all the services needed to meet their needs. The remainder could either obtain only some services (38 percent) or no services at all (10 percent). Among individuals with ASDs who received some privately funded services, the most common interventions included speech and occupational therapy (57 percent each), and behavioral therapy (54 percent).

Most survey respondents (78 percent) who were unable to receive needed services from private providers cited cost as a barrier. The issue of affordability is especially acute for individuals with severe needs or young children who require intensive interventions. In a 2008 JLARC report that evaluated proposed mandated coverage of ASDs, it was estimated that families could spend from $6,000 annually for occupational and physical therapy sessions once a week up to $75,000 annually for 25 hours of ABA-based behavioral therapy per week. On the staff survey, caregivers of individuals with ASDs reported spending an average of $12,000 per year on ASD-related services.

In order to pay for services, many families who attended a JLARC staff public input session described having to deplete their savings accounts, cash in retirement plans, take out second mortgages, and in some cases lose their home. The majority of families also reported using funds from friends and family members.

Using Health Insurance Coverage to Fund Services

Health insurance policies do not appear to consistently or fully cover ASD-related services. Based on a survey of the top 50 health insurance providers in Virginia conducted by the Bureau of Insurance in 2008, only four of the 34 respondents indicated that they provided comprehensive coverage of ASD-related services. Insurers further stated that services could be limited based on members' policy limitations, medical necessity reviews, medical policies, and covered provider types. In fact, 90 percent of individuals whose insurance policy covered ASD-related services were subject to a cap on the cost or frequency of services covered, exclusions on the types of services covered, or both, based on a JLARC staff survey of individuals with ASDs and their caregivers. Despite coverage limitations, some families reported being able to receive insurance reimbursement for certain services if providers attributed them to conditions other than ASDs, according to statements made during four public input sessions conducted by JLARC staff.

Although ASDs are medically based neurological disorders, health insurers generally indicate that it is inappropriate for them to cover ASD-related therapies. Table 8 summarizes their most commonly cited reasons, and the counterarguments advanced by individuals with ASDs, their families, and other advocates.

Table 8: Common Arguments Concerning Health Insurance Coverage for ASD-Related Therapies

Category	Opposition	Support
Habilitative vs. Rehabilitative Services	Therapies needed by individuals with ASDs are habilitative because they build a level of functioning that individuals did not previously possess, whereas health insurance has typically been designed to cover rehabilitative services that restore skills that existed previously.	Some insurance plans already provide limited coverage of habilitative services for individuals with ASDs. These plans include Virginia's Medicaid program and TRICARE, which covers military personnel and their dependents. Moreover, health insurers consistently cover the correction of congenital birth defects, which could be considered to be "habilitative" procedures.
Effectiveness of Therapies	Many treatments are experimental, investigational, or unproven for ASDs. No treatment is known to be effective for all individuals.	Many in the medical community (including the U.S. Surgeon General, the Institute of Medicine's National Research Council, and the American Academy of Pediatrics (AAP)), recognize certain therapies as research-based, including speech, occupational, physical, and behavioral therapies such as those based on the principles of applied behavioral analysis (ABA). Medical treatments are generally not effective for everyone who suffers from a given medical condition.
Educational vs. Medical Services	Behavioral interventions are educational rather than medical services, which schools are legally required to provide.	The behaviors associated with ASDs stem from a medical condition. Because these behaviors begin in childhood, they affect the ability to learn but are not, in themselves, an educational issue. The Virginia Medicaid program recognizes that school-based interventions can be medically necessary. In addition, the scope of ASD-related symptoms can affect more than the ability to learn, such as motor skills or caring for oneself. Addressing these effects is not within the mission of school systems.
Ensuring Quality	No mechanism exists to ensure that providers of behavioral services are qualified.	National licensures exist to certify behavioral analysts, and some states have created their own licenses.
Ensuring Necessity of Services	No system of case management is in place to ensure that individuals with ASDs receive only services that are needed.	Like other medical conditions, physicians could manage the plan of care for individuals with ASDs. The AAP recommends that pediatricians create "medical homes" for children with ASDs and remain actively involved in their care. Insurers can also apply utilization management processes to ASD-related services.
Mental Health Parity and Early Intervention Laws	Health insurance already covers medically necessary therapies for individuals with ASDs in order to comply with Virginia's early intervention and mental health parity laws.	Virginia's mental health parity law only requires that coverage for behavioral health be no different from coverage for other conditions. However, the law does not require services to be covered. Further, services are often deemed not medically necessary due to the aforementioned issues. The protracted appeals process can waste valuable time during which services could be provided.

Cost of Coverage	Expanding coverage to include ASD-related therapies would lead to higher insurance premiums which would, in turn, impose a hardship on businesses and increase the number of uninsured individuals.	States that have mandated insurance coverage of ASD-related therapies have experienced a relatively small increase in premiums. The purpose of insurance is to spread the cost of medical care over large groups. Early and intensive treatment can reduce the long-term costs associated with ASDs.
Number of Individuals Affected	Only those individuals covered by fully insured health plans (approximately 20 percent of insured Virginians) would benefit from health insurance mandates.	This is true of all health insurance coverage in the U.S.

Source: JLARC staff analysis of research literature and interviews with supporters and opponents of mandated health insurance coverage for ASD-related therapies.

Chapter 4

Improving Service Coordination for Virginians With Autism Spectrum Disorders

In Summary

Although multiple programs and funding sources support Virginians with ASDs, they tend to be inadequately coordinated at the State, community, and individual levels. No State entity has, to date, orchestrated the efforts of the complex network of agencies and programs serving individuals with ASDs. As a result, Virginia has lacked a mechanism to set a coherent vision for its service delivery system and to ensure the efficiency and effectiveness of existing programs. The Department of Behavioral Health and Developmental Services will assume lead responsibility for coordinating services in July 2009, but will need to prioritize its efforts to build an effective system of care. In addition, there is no centralized, reliable source of information that enables Virginians to identify the programs and funding sources available for individuals with ASDs. Furthermore, these individuals do not consistently have case managers who can facilitate access to needed programs and services. To address these issues, the State should create a centralized, comprehensive source of information, and could expand its case management services to all persons with ASDs.

Virginians with ASDs and their caregivers repeatedly express their frustration at a highly inefficient and fragmented system of care that hinders access to existing programs and resources, and leaves many individuals unserved. Due to a lack of coordination at the State, community, and individual levels, it is unclear to what extent families are accessing publicly supported programs that are already in place to serve them, or how efficiently and effectively these resources are used.

A fundamental concern raised by numerous Virginia families is the lack of services available to fully meet the needs of persons with ASDs. As the Department of Behavioral Health and Developmental Services (BHDS) begins its new role as lead agency overseeing developmental disability services, one of the key functions it can perform is to help shape the State's vision about the extent of services and supports that should be made available to Virginians with ASDs who are currently unserved or underserved.

LACK OF STATE ENTITY COORDINATING ASD SERVICES MAY UNDERMINE USEFULNESS OF EXISTING PROGRAMS

Several programs and funding sources exist to support Virginians with ASDs, but they are scattered and fragmented. Until a State entity oversees the delivery of services to individuals with all developmental disabilities, Virginia will lack a mechanism through which to develop public policy that supports its vision for serving individuals with ASDs, ensures that resources are used as efficiently as possible across programs and agencies, promotes the effectiveness of services, and addresses service gaps. BHDS is scheduled to assume the role of lead agency for developmental disabilities on July 1, 2009. This step will likely help with the development of a cohesive, efficient, and effective system of care for Virginians with developmental disabilities (Figure 7). Yet, this shift will likely take time to complete, especially given the limited additional resources that have been provided to support the agency's expanded mission.

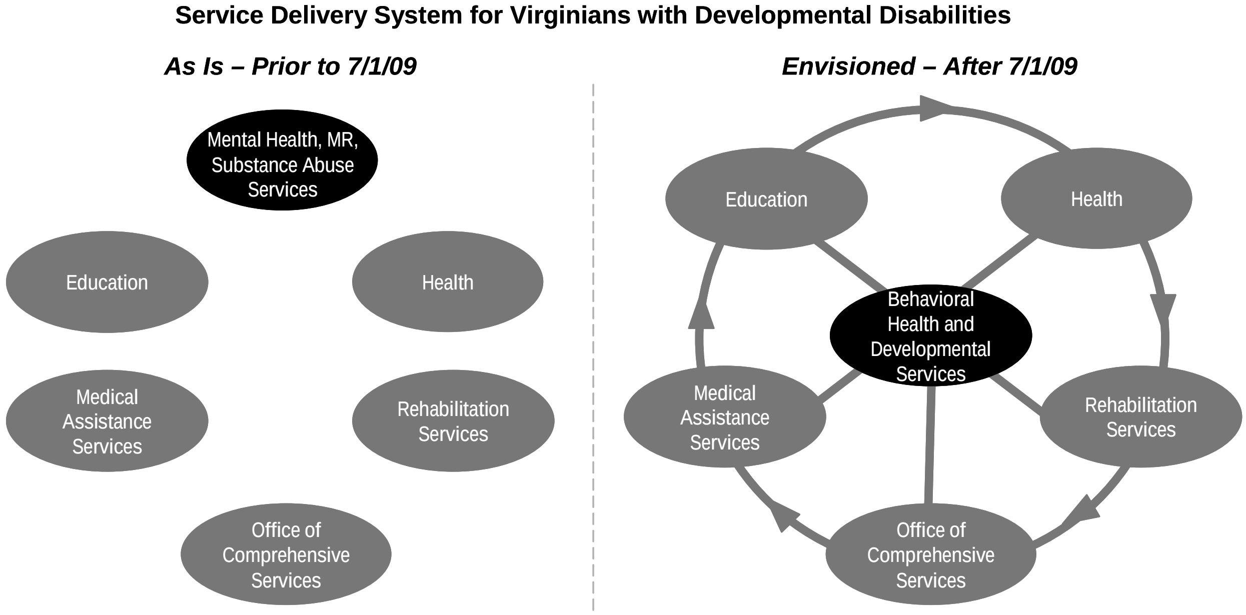
Chapter Research Methods

JLARC staff interviewed a variety of stakeholders, including staff from all agencies serving individuals with ASDs. In addition, staff surveyed individuals with ASDs and their caregivers, and received 600 responses. Four public input sessions were held across Virginia. Staff also conducted an extensive review of the research literature and practices used in other states. More details on study methods are provided in Appendix B.

Virginia Has Not Developed Comprehensive Public Policy for Individuals With ASDs

The State has not articulated a clear vision for the system of care it wishes to make available to individuals with ASDs and their families beyond its current legal obligations. In the absence of a coordinating entity, each agency has implemented programs independently and usually in response to federal and State requirements relevant to the population they serve. While important new programs have been developed (such as Medicaid waivers) to better meet the needs of persons with ASDs, these efforts have been undertaken in a piecemeal fashion rather than as the result of a careful examination of the State's entire system of care.

Figure 7: Assigning Lead State Entity Could Help Realize Common Vision, Improved Efficiency, and Greater Effectiveness



Source: JLARC staff analysis.

This approach has perpetuated the fragmentation of services and has failed to systematically bring focus to the type and scope of service needs that are not addressed by existing programs and agencies, and the impact of these unmet needs on Virginians with ASDs and their families. Without this information, the State has been unable to shape cohesive public policy about which, if any, of these unmet needs it wishes to address.

Lack of Formal Collaboration and Coordination Between State Agencies May Undermine Efficiency and Effectiveness

The absence of a lead State entity has also resulted in a lack of formalized collaboration and coordination between agencies that serve individuals with ASDs. Systematic collaboration and coordination is needed because the multifaceted needs of individuals with ASDs often cannot be addressed entirely by one program or agency, as described in Chapter 3. While the agencies that serve individuals with ASDs frequently work together on specific initiatives (such as increasing the utilization of Medicaid funds for Early Intervention Part C services, or identifying the skills and competencies needed by service providers), these efforts are generally ad hoc, short term, and limited in scope. Furthermore, collaboration is predicated upon one agency taking the initiative and the other being receptive.

Without cross-program oversight, there is also no mechanism to ensure that the complement of services available to an individual is not duplicative and that it is provided in a manner that most efficiently uses public resources. As described in Chapter 3, individuals with ASDs can be concurrently enrolled in several Virginia programs that offer similar services. While most programs provide a case manager who is responsible for overseeing the delivery of services to an individual, not all programs have this feature, such as the Elderly or Disabled with Consumer Direction waiver. In addition, it may be more effective to create programs that are designed to avoid unnecessary overlaps, rather than relying on case managers to identify redundancies after the fact. Currently, programs are generally designed by the agency responsible for their oversight, which may not be fully cognizant of the services available from other agencies.

Lastly, no entity is responsible for ensuring the collective effectiveness of all services provided. Outcomes are not tracked to gauge the effectiveness of every program, and even those programs that measure outcomes frequently do not focus specifically on individuals with ASDs. Given the unique needs and characteristics of persons with ASDs, this approach may not be sufficient to ensure that existing programs serve them effectively, as will be discussed in Chapters 6 and 7. Moreover, effectiveness tends to be measured on the basis of a program rather than a person. Because individuals with ASDs can participate in multiple programs, this piecemeal approach may not adequately capture the effectiveness of the entire complement of services received. In addition, no entity currently looks across programs and agencies to identify effective initiatives, assess what resources may be needed to enhance effectiveness, and determine whether resources should be directed toward those that have demonstrated superior outcomes. Instead, each agency performs these functions individually and may not share their findings with other departments facing similar challenges.

Assigning BHDS Responsibility for Developmental Disabilities System Appears Appropriate and Consistent With Other States

Assigning lead responsibility to BHDS provides a useful foundation for addressing many of the challenges that currently undermine the delivery of services to Virginians with ASDs.

Designating a State entity to oversee developmental disabilities could help Virginia develop a more comprehensive and coordinated approach to serving individuals with developmental disabilities, including ASDs. Selecting BHDS as the lead agency responsible for developmental disabilities was a difficult and lengthy process because numerous alternatives exist, none of which without flaws. However, this choice appears to provide a useful foundation for addressing many of the challenges that currently undermine the delivery of services to Virginians with ASDs and is also consistent with the approach followed by most other states. Further, it appears that the concerns over assigning BHDS with lead responsibility for developmental disabilities can be addressed through careful planning and thoughtful implementation.

While concerns have been raised that assigning a lead agency responsible for all developmental disabilities would not provide sufficient focus on ASDs, the national trend has been shifting toward integrating services across disabilities. All states have combined responsibility for intellectual disabilities with all other forms of developmental disabilities, rather than creating a separate agency or office overseeing ASDs. In fact, only six states have formed a separate ASD unit within the agency that oversees developmental disabilities. Furthermore, most states have aligned their developmental disabilities functions either with their mental health and substance abuse services agency (their equivalent of Virginia's BHDS), or with their disabilities agency (a structure that does not exist in Virginia).

Another key concern raised by ASD stakeholders was the potential difficulty in shifting the mission of BHDS, which has historically focused primarily on intellectual disabilities. This issue would apply to any existing agency, given that no agency currently has broad responsibility for developmental disabilities. While a new agency or office could be created specifically to build the State's developmental disability system, this approach would require a substantial ramp-up in knowledge and resources, create potential inefficiencies by adding a new layer of overhead costs, and reinforce fragmentation across disabilities.

Still, it is unclear how much BHDS will be able to accomplish in the short term, particularly given the limited resources it has received to accomplish its new mission. As documented in subsequent chapters of this report, many opportunities exist to improve the delivery of services to individuals with ASDs. The two BHDS staff hired to oversee this system will likely be unable to address each of these opportunities in the near term, even if they can use the expertise of their colleagues who focus on intellectual disabilities. These two staff will be responsible for the system of care supporting not only Virginians with ASDs, but also those with other developmental disabilities (excluding intellectual disabilities). Further, it is unclear how much authority BHDS will have to achieve greater collaboration and coordination across agencies, especially if the department has no authority over funding. Lastly, BHDS will likely struggle for acceptance in the ASD community, especially among certain advocates and caregivers who have expressed strong reservations about this choice of lead agency.

LACK OF CENTRALIZED, ACCURATE INFORMATION MAY HINDER ACCESS TO APPROPRIATE SERVICES

While an array of programs and providers exists to diagnose and treat ASDs, no coordinated source of information comprehensively addresses all key concerns of individuals with ASDs and their caregivers. In addition to imposing a burden upon Virginia families that are already experiencing a challenging situation, the lack of centralized information may also hinder them from fully understanding ASDs, seeking treatment that is effective, locating reputable providers who can successfully manage their condition, or accessing public programs and supports for which they are eligible. In the absence of a single source of information, Virginia families are relying on an incomplete patchwork of websites and informal networks to help them navigate this complex system.

Virginia Families Consistently Report Difficulties Accessing Information About ASDs and Available Services

Virginia families at public input sessions expressed great frustration with their attempts to identify and secure services needed to address ASDs.

Virginia families who participated in JLARC staff-led public input sessions repeatedly expressed great frustration with their attempts to identify and secure services needed to address ASDs. In particular, they reported "wasting a lot of time" trying to find comprehensive and objective information about ASDs and effective treatments. In addition, several attendees described difficulties finding qualified providers who either had expertise in ASDs or were willing to treat individuals with this condition. These concerns were echoed by caregivers who responded to a JLARC staff survey. In particular, survey respondents indicated that it was critical for the State to provide more information about ASDs and how to treat them, and where to find financial support for services.

Caregivers who attended public input sessions and responded to the JLARC staff survey also consistently indicated that the complex network of public programs was difficult to navigate. In part due to the lack of a lead State entity, there is no single point of entry for Virginians with ASDs and their families to learn about existing programs. While certain programs may be widely known (such as the School Part B system for which newly enrolled students with disabilities will likely be screened), others may require guidance that is currently out of reach for families. For example, many caregivers indicated not having heard about the Early Intervention Part C program until after their child had turned three and was no longer eligible, based on a JLARC staff survey.

In addition, it may not be apparent that certain programs, such as the Elderly or Disabled with Consumer Direction waiver, which acts as an alternative to nursing home care, are in fact available to individuals with ASDs of all ages. As a result, these programs may be greatly underutilized despite the array of useful services and financial support that they can offer to persons with ASDs and their families.

Most Families Rely on the Internet and Other Caregivers for Information, Which May Not Always Be Adequate or Reliable

In the absence of a centralized source of information, Virginians with ASDs and their families frequently turn to an array of sources that may not be consistently adequate or reliable. According to a JLARC staff survey of caregivers, other parents are the most useful source of information about ASDs and available providers, followed by the Internet and advocacy groups. Several participants in public input sessions discussed their efforts to educate other parents about available public supports in response to the lack of State guidance. In fact, one advocacy group in the Tidewater area resorted to sponsoring parent-led workshops about available Medicaid benefits because many of their members were unaware of programs for which they could apply. In addition, numerous websites offer information about ASDs and treatment options: as an illustration, an Internet search on “autism” returned nearly 18 million matches. Lastly, many ASD advocacy groups have been formed at the national and State levels to provide information and offer support to caregivers. The best-known national organizations include the “Autism Society of America,” which has four local chapters in Virginia, and “Autism Speaks.”

While existing sources of information fulfill an important function, they do not appear to fully meet the information needs of Virginians with ASDs and their families, and can in fact be overwhelming. One respondent to the JLARC staff survey of caregivers indicated that the abundance of information sources was "more confusing than helpful." In addition, information provided by other parents and Internet sites, however well intended, may not be consistently reliable. In particular, ASD stakeholders interviewed by JLARC staff indicated that information about the effectiveness of ASD interventions should be interpreted very cautiously because false claims are commonly made about ASD "cures."

Lastly, while the State has several tools in place to help Virginians locate providers (such as the 2-1-1 hotline), these resources are often overly generic. For example, multiple caregivers described their cumbersome attempts to cull through long lists of specialists before finding one who was willing and qualified to treat their child. Commonwealth Autism Service offers ASD-specific information and referrals to thousands of families, but is not currently staffed or designed to act as the State's single point of contact for all Virginians with ASDs and their families.

COMPREHENSIVE CASE MANAGEMENT NOT CONSISTENTLY AVAILABLE TO INDIVIDUALS WITH ASDs

Individuals with ASDs and their caregivers are often the primary coordinators of services across programs and providers.

Although many Virginia programs that serve individuals with ASDs provide case management services, case management is not consistently comprehensive or available throughout life stages. Consequently, individuals with ASDs and their caregivers are often the primary coordinators of services across programs and providers. However, these persons may not consistently possess the skills and resources to adequately fulfill this function. The time required to coordinate services appears to frequently undermine caregivers' ability to be fully employed.

The scope of available case management services does not always include all providers who may be involved in the care of individuals with ASDs. In particular, School Part B and vocational rehabilitation case managers generally focus on services directly related to their core missions of education and employment, respectively. In addition, most individuals with ASDs will transition between multiple systems of case management during their lifetime because most programs are available only during certain life stages. One notable exception is for Medicaid waivers, through which enrolled individuals can receive case management services for much of their lifetime. Some families also reported being concerned about the impartiality of case managers who may be acting as gatekeepers seeking to minimize their agency's costs. Lastly, the current system may be inefficient because individuals with

ASDs can be enrolled in multiple programs and, therefore, have multiple case managers.

Caregivers must often bridge gaps in the case management services available from public programs. Participants in JLARC staff-led public input sessions described having to learn about the various publicly supported systems that currently serve individuals with ASDs, advocating for publicly supported services, obtaining and subsequently coordinating plans of care across multiple specialists and publicly supported programs, finding private providers, and securing financial support all while tending to the needs of a disabled child.

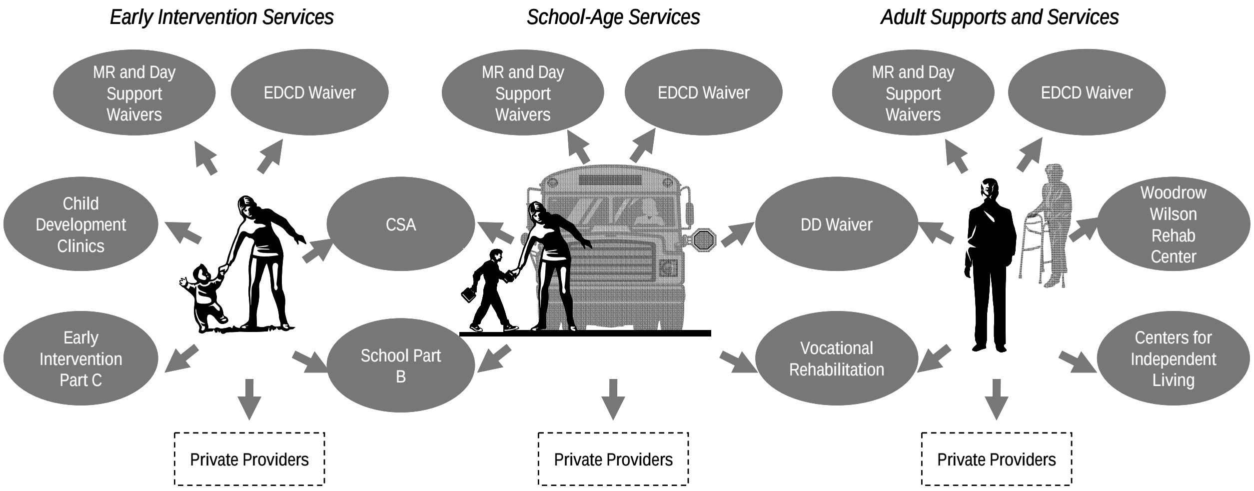
While it is expected that families should be active participants in their dependent's care, the level of involvement currently required of caregivers may lead to inadequate service coordination that could compromise outcomes. In particular, this process may be inadequate because caregivers are generally not professionals who are qualified to effectively manage their child's care and evaluate the quality of providers. Not all caregivers have the skills or resources to act as case managers. For example, a respondent to a staff survey of caregivers indicated great difficulty managing her child's care as a single parent with a full-time job. Lastly, it may be inefficient and unduly burdensome for caregivers to learn how to navigate a service delivery system that changes across life stages, as well as to individually develop relationships with providers (Figure 8).

The level of involvement required to address the needs of individuals with ASDs can place a tremendous emotional toll on families, but also commonly affects their employment. Nearly 80 percent of caregivers reported in a JLARC staff survey that caring for an individual with an ASD negatively impacted the employment status of someone in the family, most commonly causing them to stop working (32 percent), take a less demanding job (19 percent), or work fewer hours (15 percent).

OPTIONS TO IMPROVE SERVICE COORDINATION FOR VIRGINIANS WITH ASDS

Improving service coordination could ensure that Virginia builds a cohesive system of care comprised of programs that operate as efficiently and effectively as possible, and are easily accessible to all eligible individuals. To optimize results, steps could be taken to improve coordination at the State, community, and individual levels.

Figure 8: Virginians With ASDs and Their Caregivers Act as Case Managers to Access Programs That Vary Across Lifespan



Source: JLARC staff analysis of Virginia program documentation and eligibility criteria.

Promoting State-Level Accountability and System Coordination

While the advisory group convened by the Secretary of Health and Human Resources in 2008 developed an implementation plan that includes many important steps, several items could be emphasized to ensure that BHDS fulfills its new mission successfully and seamlessly. In particular, it will be important for the agency to obtain assistance from all ASD stakeholders in order to build a system of care in Virginia. In addition, the State will need to consider whether and to what extent it wishes to further support individuals with developmental disabilities, including ASDs, by offering services currently unavailable. Finally, BHDS could take necessary steps to ensure that existing programs are using resources efficiently and yielding effective results.

BHDS Efforts Could Focus on Strategic Planning. Because numerous challenges currently exist, it will be critical for BHDS to clearly define the responsibilities of the two individuals hired to oversee the State's newly created developmental disability system. In particular, the agency will need to determine whether these staff should address issues that are immediate but tactical, such as fielding citizens' questions and concerns, or focus on strategic planning aimed at building a system of care. Given the fragmentation of today's system, it appears that a more strategic focus on developing a system of care for individuals with developmental disabilities of all ages would best serve the State.

Virginia Could Create an Advisory Group to Support BHDS. In light of the limited staff available to begin building a comprehensive system of care and the complexity of this task, the State could partner with an advisory workgroup comprised of key ASD stakeholders. BHDS already relies on a similar but informal workgroup that has historically guided its efforts in serving Virginians with intellectual disabilities, and was recently reshaped to reflect the agency's expanded role with other developmental disabilities. The Advisory Consortium on Intellectual and Developmental Disabilities (TACIDD) could become formalized through the Code of Virginia and report on its progress annually.

In addition to lending manpower and expertise, this group could also help BHDS gain public confidence by involving community members, and foster collaboration across agencies and programs. Membership of this workgroup could be expanded where needed to include individuals with ASDs, caregivers, and advocates; providers; organizations with expertise in ASDs, such as Commonwealth Autism Service (CAS); decision-makers from all agencies that serve individuals with ASDs and their families; and staff from BHDS who could act as the workgroup's coordinators. Representatives could be appointed by the Governor to ensure that members have sufficient knowledge and authority to make decisions.

While the Board for People with Disabilities acts as Virginia's developmental disability council for federal purposes, its focus is more strategic and not in line with the day-to-day tactical guidance that could be offered by TACIDD. Still, the Board's involvement and guidance will likely be an important strategic resource for BHDS. The Virginia Autism Council already convenes experts in ASDs, but their efforts have centered on training service providers rather than strategic system development, and their members are generally not decision-makers.

State May Need to Define the Extent of its Commitment to Developmental Disabilities. Before plans to build a system of care can be made, the State must determine the role it wishes to play in serving individuals with developmental disabilities, including ASDs. Conducting a needs assessment could be an important first step toward identifying service gaps and populations that are not adequately served by existing programs, and creating a roadmap to build a comprehensive system.

In its new role, BHDS could take the lead in policy planning, including shaping the debate about the extent of State resources that should be allocated to developmental disabilities. In particular, Virginia will need to consider how to allocate resources in its new developmental disability system, and whether its commitment to developmental disabilities will be on par with its historical support for intellectual disabilities. Although intellectual disabilities are twice as common as ASDs, the State has thus far made a disproportionately greater investment in supporting individuals with intellectual disabilities. This disparity is illustrated by the allocation of waiver slots, as there are approximately 8,000 MR waiver slots for individuals with intellectual disabilities compared to 600 DD waiver slots for persons with other types of developmental disabilities. Consequently, Virginians with ASDs are currently less likely to obtain waiver services if they do not have a co-occurring intellectual disability diagnosis.

BHDS Could Explore Potential Role of CSBs. Internally, BHDS will need to explore the extent to which its shift in mission will affect resource allocations. The agency's current budget provides for 19 staff with a focus on intellectual disabilities and only two who will focus on all other developmental disabilities. Similarly, community services boards are primarily funded to serve individuals with intellectual disabilities who are enrolled in the MR waiver, and seldom serve individuals with other developmental disabilities. Consideration could be given to the role that CSBs could play, including whether it should parallel the expanded mission of BHDS and include individuals with developmental disabilities who are not enrolled in waivers. For example, CSBs could function as regional centers serving individuals with ASDs through all life stages, and offer services that might range from case management, to diagnostic, to direct services, as will be discussed further in Chapters 5 through 8.

At least two-thirds of other states fund developmental disabilities services that do not rely on Medicaid in general or waivers specifically, and most deliver these services through regional centers. Currently, no additional funding has been allocated to CSBs for them to begin serving individuals with developmental disabilities other than intellectual disabilities. Consequently, the shift in BHDS's mission is unlikely to translate into changes in service delivery, at least in the near term.

Steps Could Be Taken to Maximize Efficiency. BHDS could consider ways to maximize efficiency across the various programs and agencies that currently serve individuals with ASDs. This might include exploring whether BHDS should become responsible for certain programs that serve persons with developmental disabilities but are currently administered by other agencies. For example, it may be efficient for BHDS to assume operational responsibility for administering the Developmental Disabilities (DD) waiver, similar to the function it performs for the Mental Retardation (MR) and day support waivers.

BHDS and the Department of Medical Assistance Services could also explore whether the multiple waivers supporting individuals with developmental disabilities should be consolidated into one program. A consolidated waiver program for developmental disabilities could reduce administrative overhead, better integrate services across disabilities, and parallel the State's move toward a single developmental disabilities system.

Another program that could potentially fit under BHDS is the network of child development clinics, which screen children for developmental disabilities and are currently overseen by the Virginia Department of Health. Potential overlaps in services could also be considered, such as the provision of case management across multiple programs in which an individual can be concurrently enrolled.

Effectiveness Could Be Improved Through Outcomes Measurement and Best Practices Sharing. BHDS could also focus on ensuring the effectiveness of existing programs serving individuals with ASDs and their caregivers. In particular, the agency could develop common goals across agencies and programs, ensure that data on outcomes are consistently collected and analyzed, and create a mechanism to measure outcomes that center on individuals rather than programs. In addition, the agency could use outcome measures to identify and share best practices, as well as ascertain whether particular programs need assistance to improve their effectiveness.

Enhancing Access to Information About Community Resources

To help Virginians with ASDs and their families make informed decisions about needed services and access existing programs, the State should make available a centralized, comprehensive, and accurate source of information. In particular, this resource could include general information about ASDs, research about various treatment methods, guidance about available Virginia programs, and contact information for service providers and support groups. Several State and national organizations already provide useful information that could be validated and incorporated into the State's central resource.

Several mechanisms could be used to deliver this information, including a guidebook, website, and staffed clearinghouse. While all of these options offer information that will go a long way to helping families navigate Virginia's system, tools that offer opportunities for individualized guidance, such as a staffed clearinghouse, are likely to be the most useful but also the most costly (Table 9).

Any of these tools could be implemented by one of several existing entities. As the new lead entity for developmental disabilities, BHDS could oversee the development of a source of information about ASDs. Resources could be provided to designate as the

Table 9: Advantages and Disadvantages of Options to Improve Access to Information

Option	Advantages	Disadvantages
Develop a guidebook	Comprehensive and centralized Widely available, especially if online	Static and cumbersome to update Not customizable Not personalized because no "live" guidance
Create an interactive website	Easy to update Comprehensive and centralized	Requires maintenance and ongoing oversight to keep updated Not personalized because no "live" guidance Requires Internet access
Staff an information clearinghouse	Personalized due to "live" guidance Comprehensive and centralized	Requires training to ensure staff knowledge is up-to-date

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

State's central source of information and increase the capacity of the Commonwealth Autism Service (CAS), which is already staffed by knowledgeable professionals who provide information and referrals. Alternatively, CSB personnel could potentially staff a clearinghouse, but would require training and additional resources to assume this new role. Lastly, a focus on ASDs could be incorporated into the State's 2-1-1 service, which would require additional staff training and website modifications.

Recommendation (1). The Department of Behavioral Health and Developmental Services should collaborate with relevant State agencies and stakeholder groups to design a centralized, comprehensive, and reliable source of information to educate Virginians about (1) autism spectrum disorders, (2) research findings about treatment approaches and interventions, (3) publicly supported programs and supports, (4) private providers specializing in autism spectrum disorders, (5) support groups, and (6) any other relevant information identified by stakeholders. The department and stakeholders should determine the mechanism most suitable for delivering this information, such as a guidebook, website, or staffed clearinghouse, and the entity best suited to create and administer the mechanism selected.

Ohio's Parent Guide to ASDs

The Ohio Center for Autism and Low Incidence, which is a project of the state's department of education, developed and maintains a comprehensive manual designed to help parents access the information they need to care for individuals with ASDs at all stages of their lives. The manual contains 277 pages, is available online, and includes sections that address (1) what ASDs are, (2) screening and diagnosis, (3) living with ASDs, (4) interventions, (5) accessing educational services, (6) social service programs, (7) advocacy and disability awareness, and (8) future planning. The document also includes useful forms and guidance that parents can follow to ensure access to services for which their child is eligible.

Developing a Guidebook Could Provide Useful but Static Guidance to Families. Developing a guidebook is a common and relatively low-cost option for conveying relevant information to individuals with ASDs and their families. This resource could include sections that encompass all subjects in which Virginia families have expressed an interest. Copies of the guidebook could be distributed by practitioners, such as Early Intervention Part C and school personnel, or health care providers. It could also be made available on the websites of relevant State entities. Although several states have developed this type of resource, Ohio's *Parent Guide to Autism Spectrum Disorders* is an excellent example of the scope and quality of information that can be conveyed. Ohio's guidebook could be used as a starting point and customized with information specific to Virginia's programs and providers.

Creating an Interactive Website Could Offer Customized, Up-to-Date Information. Using a website to disseminate information to Virginians with ASDs and their families would present several advantages over a guidebook. The website content could be updated as frequently as necessary to reflect changes in research findings, programs, and available providers. In addition, the information presented could be customized to meet individual needs. Rather than having to cull through a voluminous guidebook, individuals could search for specific topics of interest, such as financial supports or Virginia programs. Search engines could be created to identify providers based on their location, specialty, qualifications, and the age range of clients whom they serve. Further, a website could be built upon to fulfill a variety of related purposes, such as offering training to parents and providers. Numerous states (such as Kansas, Ohio, and Maryland) have implemented such websites, which could be used as a model for a Virginia-specific resource.

Staffing an Information Clearinghouse Could Provide Individualized Support. While a website could be customized to display the most relevant information, having access to professionals knowledgeable about ASDs and available resources would best address the specific needs of individuals with ASDs and their caregivers. Because the autism spectrum is so broad and characterized by a wide range of symptoms, caregivers will likely have questions that have not been anticipated or cannot be adequately answered by a website, and not all can access the Internet. Virginia recognized the limitations of websites by making its 2-1-1 service available by phone as well as online.

Improving Coordination of Individual Care

Effective case management is critical to ensuring that resources are used in the most efficient and effective manner. Furthermore, case managers can also act as an important source of information for linking individuals with ASDs and their families to available programs and services. The options available to offer more comprehensive case management have advantages and disadvantages, which are summarized in Table 10.

Encouraging Virginia Physicians to Use Medical Home Model. The State could encourage physicians to act as the medical home of individuals with ASDs. Medical homes are "a model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective care," according to the American Academy of Pediatrics (AAP). Although the concept dates back to the late 1960s, the AAP and sev-

Table 10: Advantages and Disadvantages of Options to Improve Case Management

Option	Advantages	Disadvantages
Encourage physicians to act as medical homes	Recommended by AAP Consistent with medical management of other conditions	Cannot be required of physicians Requires additional time that physicians may not have Does not help individuals without a primary physician
Train individuals with ASDs / caregivers on effective case management	Consistent with shift toward self-directed care Actively engages individuals and caregivers with decisions affecting care Builds upon existing process	Does not help if not willing or able to serve as case manager Requires substantial time investment Requires each individual to build knowledge base
Expand role of existing case managers	Shifts burden from client to professional case manager Builds upon existing process	Does not help individuals currently without case managers Requires training and learning about community resources
Expand and centralize case management services in regional offices	Available to everyone with ASDs Regionally dispersed Person-rather than program-centered case management	Requires ramp-up of knowledge and resources Reallocates resources from existing programs to regional offices

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

eral other medical organizations adopted joint principles in 2007 that describe the role of medical homes as coordinating and integrating care across the health care system and the patient's community.

The federal Healthy People initiative has set a goal for all children with special health care needs, including those with ASDs, to have a medical home. The State could build upon ongoing initiatives to expand the reach of medical homes in Virginia, although this approach will likely not reach all Virginians with ASDs because it cannot be required of physicians, and not everyone has a designated medical care provider.

Training Individuals With ASDs and Caregivers on Effective Case Management. Training could be offered to Virginians with ASDs and their caregivers, who are already often acting as their own case managers. Training could ensure that those who want to manage their care have the tools and knowledge to do so effectively, especially with respect to selecting providers. BHDS and DMAS have already created training materials to help waiver recipients make hiring decisions for certain providers, such as personal assistants. This concept could be expanded to design materials on other topics of interest to families who act as case managers. Training could be made available online for greater flexibility, or offered in person. This approach would still require a substantial time investment which may not be feasible for all families.

Expanding Role of Existing Case Managers. Program case managers could be tasked with coordinating services across all programs and providers involved in the care of an individual. While Early Intervention Part C and Medicaid waiver case managers already largely fulfill this function, other case managers appear to coordinate primarily services provided within their programs. For example, while schools can include private providers in a child's Individualized Education Program planning, this procedure is not standard and does not appear to be routinely used, based on the input of caregivers. While this approach would build upon an existing infrastructure, it would only help Virginians who are enrolled in publicly supported programs that offer case managers.

Expanding and Centralizing Case Management in Regional Offices. Case management services could also be delivered through regional offices, either for individuals who currently do not have a case manager or to all individuals with ASDs. Individuals could be given the choice to use staff from regional offices or hire private case managers, as is the case for DD waiver recipients. Assigning case managers to individuals with ASDs who currently lack this service could help raise awareness of the various programs and services that exist in the community. Alternatively, all case management functions could be consolidated into a regional model.

One of the key benefits of this approach is that individuals could participate in a single, cross-agency case management system throughout all life stages, rather than changing case managers with every new program in which they are enrolled. Further, consolidating case management functions could also result in greater efficiency, because individuals with ASDs who participate in multiple programs concurrently can also have multiple case managers. Savings could be used to extend case management services to individuals with ASDs who are currently unserved.

Regional case management could be provided by expanding upon the 40 CSBs that deliver services for BHDS. Implementing this option would further integrate the State's service delivery system, given the CSBs' relationship to BHDS and frequent co-location with Early Intervention Part C offices. However, this shift could be difficult to achieve: CSB staff generally lack experience serving persons with ASDs, unless they have a co-occurring intellectual disability, and would require additional training as well as more staff to meet the needs of this new client population. Further, concerns have been raised by ASD stakeholders as well as the BHDS Inspector General that CSBs face substantial difficulties serving existing clients.

Alternatively, new regional offices could be created by expanding upon university-based autism centers and clinics that exist in several Virginia locations. This approach would enable families that seek ASD diagnoses from clinics to also link with a case manager with access to clinical expertise. While several states operate university-based clinics that offer case management services, this option would require significant resources in Virginia because this service would be new, and existing clinics are not available throughout the State.

Summary of Options to Improve Service Coordination and Implementation Considerations

In addition to having different policy merits, options described in this chapter vary in terms of the financial and human resources required, the extent to which they address the issues discussed in this chapter, and the time needed for implementation. Figure 9 (next page) summarizes these implementation considerations and reflects the best judgment of JLARC staff based on discussions with experts and knowledge gained during this review. To facilitate the State's decision whether and how to improve service coordination, BHDS should collaborate with relevant stakeholders to weigh policy and implementation considerations, and identify which options are most suitable to improve system coordination, access to information, and coordination of individual care in Virginia.

Recommendation (2). The Department of Behavioral Health and Developmental Services should collaborate with relevant stakeholders to (1) evaluate the options for promoting State-level accountability and coordination of services for Virginians with autism spectrum disorders, enhancing access to information about community resources, and improving the coordination of individual care; and (2) identify no later than March 31, 2010, which, if any, options are most beneficial to pursue.

Figure 9: Implementation Considerations for Options to Improve Service Coordination

Major Goal	Resources Needed	Extent to Which Addresses Major Goal [a]	Time Needed to Implement
Promoting State-Level Accountability and System Coordination			
Prioritize key steps in implementation plan	--	★★	🕒🕒
Enhancing Access to Information About Community Resources			
Develop guidebook	↓	★★	🕒
Create interactive website		★★★	🕒🕒
Staff information clearinghouse		★★★	🕒🕒
Improving Coordination of Individual Care			
Encourage physicians to act as medical homes	↓		🕒🕒
Train individuals/caregivers on case management		★★	🕒🕒
Expand role of existing case managers		★★	🕒🕒
Expand and centralize case management in regional offices		★★★	🕒🕒🕒

Least ↓ Most

★	Somewhat
★★	Substantially
★★★	Greatly
🕒	< 6 Months
🕒🕒	6-18 Months
🕒🕒🕒	> 18 Months

Note: --, Rating is not applicable because only one option is listed.

[a] Ratings reflect the extent to which each option addresses the major goal described in the gray-shaded row.

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

Chapter 5

Facilitating Earlier Identification and Diagnosis of Autism Spectrum Disorders

In Summary

Even though the research literature suggests ASDs can be diagnosed between ages two and three, it appears that Virginia children are often diagnosed later. Being identified and diagnosed with an ASD as early as possible enables children to begin early intervention services, which can improve outcomes. Four main issues appear to contribute to delayed diagnoses: (1) inadequate information and understanding regarding child development, ASDs, and what to do when early signs of an ASD are noticed; (2) lack of regular and standardized developmental screenings; (3) delays when parents begin to pursue a diagnosis; and (4) limited information about how to obtain services once ASDs have been identified and later diagnosed. A variety of options could be used to facilitate earlier identification and diagnosis of ASDs, ranging from launching a public awareness campaign to expanding diagnostic capacity.

Identifying the warning signs of ASDs through a screening and making a definitive diagnosis are both critically important to ensuring the provision of timely and appropriate services. Once children have been identified as potentially being on the autism spectrum, Early Intervention Part C services or other appropriate services can be initiated even without a definitive diagnosis. Although the American Academy of Pediatrics (AAP) recommends not delaying the provision of services until a diagnosis is obtained, a definitive ASD diagnosis is important because it qualifies children for intensive early intervention programs tailored to meet specific ASD-related needs. Receiving intensive services at an early age may reduce long-term costs to caregivers and to the public delivery system. As described in Chapter 2, intensive early intervention tailored to the needs of children with ASDs has the potential to significantly improve individuals' level of functioning and outcomes.

SOME VIRGINIA CHILDREN APPEAR TO BE DIAGNOSED WITH AN ASD LATER THAN IS DESIRABLE

While most recent clinical studies indicate that an experienced clinician conducting a comprehensive evaluation can make a stable and accurate ASD diagnosis between age two and three, evidence suggests that ASD diagnoses are occurring later in Virginia. Some children may ultimately move to a different place on the autism spectrum (for example, from a diagnosis of autistic disorder to one of Asperger's syndrome), although most children diagnosed by age two to three retain an ASD diagnosis several years later. Further,

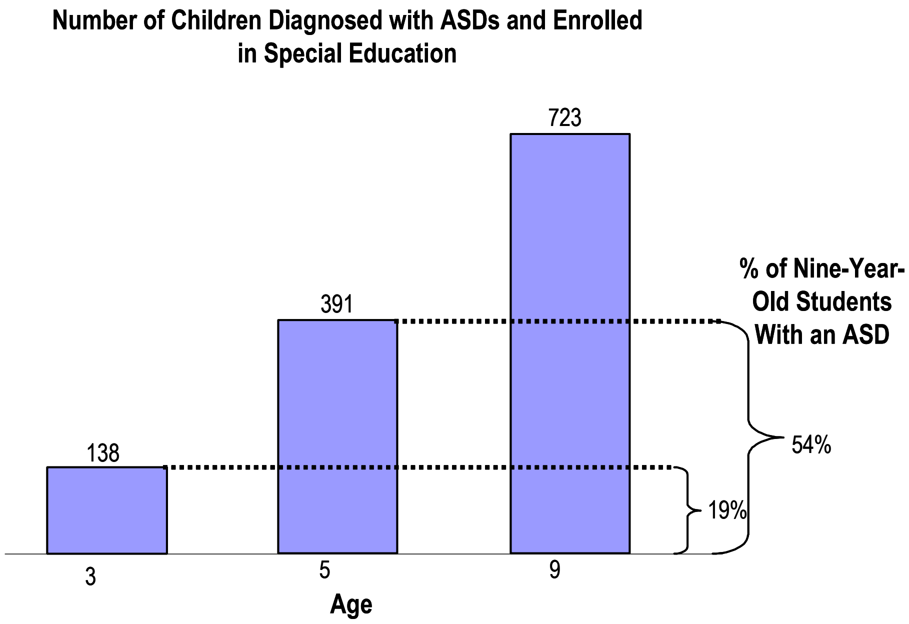
Chapter Research Methods

JLARC staff interviewed a variety of stakeholders, including representatives from Commonwealth Autism Service and Autism Speaks; experts from Virginia Commonwealth University and the University of Virginia; staff from the departments of Health, Behavioral Health and Developmental Services (formerly DMHMRSAS), and Medical Assistance Services; and, personnel at eight local Early Intervention Part C offices. JLARC staff also facilitated a roundtable with Virginia AAP-member pediatricians, and conducted four public input sessions around the State for individuals with ASDs and their caregivers. Staff surveyed individuals with ASDs and their caregivers, and received 600 responses. Additionally, staff conducted an extensive review of the research literature and practices used in other states. Additional details on study methods are available in Appendix B.

recent studies that examined video footage of children subsequently diagnosed with ASDs found that signs of ASDs could be detected by age one.

Half of children are diagnosed by age three, according to the caregivers of children with ASDs age eight or under who participated in the JLARC staff survey. Data from Virginia public schools show that the number of children identified with an ASD for special education purposes peaks at age nine. The number of students with ASDs receiving special education services at age three is only 19 percent of the number of students with ASDs at age nine, and the number of students with ASDs at age five is half that of students with ASDs who are nine years of age (Figure 10). This trend appears consistent over the last three years. While students can receive special education services without being identified with an ASD, an ASD diagnosis helps to ensure that children receive services designed to effectively address their condition. According to experts interviewed by JLARC staff, the age of diagnosis in the Commonwealth may occur as late as ages six or seven.

Figure 10: Few Children Enrolled in Special Education Are Identified With an ASD by Age Three (2007)



Note: Data do not reflect children with identified ASDs who were not receiving special education services, or children with ASDs who were designated as "developmentally delayed," which is allowable until age eight under the Virginia Special Education regulations in effect prior to 2009.

Source: JLARC staff analysis of U.S. Department of Education Individuals with Disabilities Education Act data, 2007.

PARENTS OFTEN DELAY SEEKING PROFESSIONAL HELP AFTER NOTICING EARLY SIGNS OF ASDs

While Virginia parents appear to recognize the early signs of ASDs, they do not appear to consistently seek professional help in a timely fashion. Parents are usually children's primary caregivers, and most respondents (80 percent) to a JLARC staff survey of caregivers indicated that a parent was the first person to notice signs of an ASD. Additionally, many parents who participated in JLARC staff-led public input sessions indicated that they were the first person to notice delayed or atypical development, often before their child's second birthday.

Caregivers waited an average of five months to seek professional help after first noticing symptoms.

Even when parents report being the first to notice atypical or delayed development in their children who are ultimately diagnosed with ASDs, they frequently wait several months to act upon their concerns. Caregivers of children age eight or under waited an average of five months to seek professional help after first noticing symptoms, based on the staff survey of caregivers. Consequently, it appears that caregivers may require information about which signs and symptoms are of concern and what to do when they are first noticed. For example, most local Part C offices engage in public outreach about child development, but each local office decides what its outreach effort will involve and who it will target. In some cases, local Part C offices may limit their outreach to local pediatricians who may not pass the information on to patients, or to educational displays at county fairs where only those attendees who view the display would receive the information.

CHILDREN MAY NOT RECEIVE CONSISTENT SCREENING

Despite AAP guidance, Virginia pediatricians do not appear to be consistently using standardized instruments to screen children for ASDs at the prescribed intervals. While the AAP has conducted outreach, not all physicians are aware of these guidelines, especially family practitioners. In addition, a burdensome reimbursement process may preclude physicians from performing screenings.

Children Do Not Appear to Receive Recommended Screenings

Although guidance from the AAP recommends that a child's pediatrician perform developmental surveillance at all well-child check-ups and administer ASD-specific screening instruments at the 18- and 24-month well-child check-ups, Virginia physicians do not appear to have consistently implemented these recommendations. The AAP's guidelines have two major components that are seemingly inconsistently implemented: (1) screening for ASDs at 18 months and 24 months, or whenever developmental concerns are raised, and (2) using a standard validated instrument.

While no Virginia-specific data exist to quantify the extent to which screenings are conducted at the prescribed intervals, the experience of other states and interviews with Virginia stakeholders suggest that not all children are screened when they should be. The Ohio Department of Health found that even after providing training on screening children for ASDs, pediatric practices that volunteered to participate screened only 39 percent of patients during 24-month well-child check-ups. Additionally, although current guidelines advise physicians to conduct an ASD screening if caregivers express concerns about early signs of ASDs, some Virginia physicians still appear to advise caregivers to wait before pursuing further screening, evaluation, or services. While the AAP began to issue guidelines in 2001 and updated them in 2007, the caregivers of 36 percent of Virginia children with ASDs under eight were told to "wait and see" or not to worry when they first brought concerns to a medical professional, according to a JLARC staff survey. Caregivers who provided public comment to JLARC staff also indicated that when they voiced developmental concerns, physicians often told them that their child would "grow out of it."

Parents indicated that when they voiced developmental concerns to their child's physician, they were told that their children would "grow out of it."

Virginia pediatricians do not appear to consistently use a standard instrument to screen children, and instead observe children's behaviors during office visits. This informal clinical observation may not consider the child's behavior in other environments or detect subtle developmental delays. Studies indicate that assessments of developmental status are less accurate when physicians use only informal clinical impressions rather than formal screening instruments.

According to physicians, local Part C staff, and other stakeholders interviewed by JLARC staff, a minority of Virginia physicians use formal ASD screening instruments. Additionally, only 22 percent of respondents to a JLARC staff survey of caregivers indicated that their physician used a standardized screening instrument when concerns regarding development were expressed. Similarly, on a national level, physicians do not appear to have implemented ASD screening recommendations. A 2005 study indicated that despite the AAP's efforts, only 23 percent of general pediatric practitioners reported using standardized instruments for developmental screenings.

Difficulty Obtaining Reimbursement Reduces Screenings Performed

National studies indicate that difficulty obtaining reimbursement is the primary barrier to performing ASD screenings. Virginia pediatricians interviewed by JLARC staff also indicated that obtaining reimbursement can be cumbersome and act as a deterrent against conducting screenings, despite their societal benefit. They indicated that while receiving reimbursement is possible, some insurance companies require extensive documentation and may repeatedly deny claims until they have become familiar with this service. In the absence of appropriate reimbursement for screening, physicians bear the cost burden for these services.

Various screening instruments exist, and a 2001 study found that a developmental screening typically costs between $11 and $82, depending on the instrument used. This cost is composed of two portions: (1) the cost of administering the instrument, and (2) the cost of providing consultation on the results of the screening. For example, the administration costs (and thus the total cost) will be significantly lower for a screening tool such as a questionnaire that can be completed by a parent with limited or no assistance from office personnel versus a screening tool that requires a physician to administer it.

Physicians May Lack Awareness of Developmental Screening Guidelines

Another factor influencing the limited number of pediatricians implementing ASD screening recommendations may be that physicians are simply not aware of the guidelines. Although the AAP has been very active in developing and promoting implementation of their developmental screening guidelines, not all pediatricians are members of the AAP. Even those who are AAP members may not be influenced by the guidelines.

A study conducted by the AAP suggests that the issuance of developmental screening practice guidelines had only a limited effect on the practice of member pediatricians. Early Intervention Part C providers in rural areas indicate that physicians in their communities are less likely to be aware of ASDs and screening their patients than in other areas of the State. Additionally, children who live in rural areas of the State may be more likely to see a family physician for their medical care instead of a pediatrician, who is more likely to stay informed regarding AAP recommendations.

PARENTS MAY EXPERIENCE DELAYS BETWEEN SCREENING AND DIAGNOSIS

Many parents in Virginia experience delays in obtaining an evaluation and ultimately in receiving a diagnosis to confirm screening results. These delays can preclude children from receiving the appropriate types and intensity of services as early as possible, when interventions can be most effective. Delays can occur when pediatricians fail to acknowledge parental concerns and make referrals to a specialist, and because the limited number of

Virginia specialists often have lengthy waiting lists for appointments.

Pediatricians May Not Validate Parental Concerns and Make Timely Referrals

Pediatricians rarely diagnose ASDs, and instead generally refer children to specialists for further evaluation when screenings indicate that an ASD may exist. However, as previously indicated, many parents who provided input to JLARC staff indicated that when they expressed developmental concerns, their physician dismissed their concerns, often telling them that the child would "grow out of it" and to "wait and see." When physicians fail to validate the developmental concerns of parents, they may not make a referral for a diagnostic evaluation as soon as concerns are first observed. As a result, the child may wait longer than necessary to receive a diagnosis and services.

Virginia May Not Have Enough Clinicians to Promptly Diagnose Children With ASDs in a Multidisciplinary Environment

Virginians with ASDs must often wait for several months to receive a formal diagnosis, and even longer for comprehensive assessments from multidisciplinary teams. In a JLARC staff survey of caregivers, two-thirds of respondents indicated having to wait for a diagnosis: approximately a quarter waited one to two months, another quarter between three and six months, and 18 percent longer than six months. However, 33 percent reported no wait to receive a diagnostic appointment. Only eight percent of respondents indicated receiving a diagnosis from a multidisciplinary team, which is considered a best practice. The thorough diagnosis provided by this team can act as a "road map" for future interventions by supplying detailed information about the child's development, behaviors, strengths, weaknesses, skills, and medical condition. Multidisciplinary assessments are often available in urban centers, but physicians at these centers reported having long waiting lists. In the absence of sufficient capacity to provide multidisciplinary evaluations, most Virginians appear to be receiving their ASD diagnoses from developmental pediatricians, neurologists, or psychologists.

CAREGIVERS APPEAR TO NEED MORE PROFESSIONAL GUIDANCE IN PURSUING SERVICES

Virginians with ASDs appear to experience delays in receiving services in part because their caregivers receive insufficient information after they are screened and subsequently diagnosed. Additionally, while some ASD specialists and clinics provide comprehensive plans of care, it appears that most plans are drafted by staff from public programs, which often have a limited scope. The lack of information that precludes individuals with ASDs and their caregivers from accessing information may also preclude professionals from offering greater guidance.

Caregivers Appear to Have Insufficient Knowledge of How and When to Begin Accessing Services

Although children should begin receiving early intervention services as soon as they are suspected of having an ASD, many do not begin services before they receive a definitive ASD diagnosis. When a child first has an abnormal ASD screening, best practices, according to the AAP, call for the child to be simultaneously referred for further evaluation and to early intervention services. However, an average of one year elapsed between the time when caregivers first sought professional help and the time when services were initiated, based on responses from caregivers of children age eight or under. An issue that may affect caregivers' ability or inclination to initiate services may be the level of direction they receive from medical professionals.

Medical professionals also do not appear to consistently provide useful guidance after they have diagnosed individuals with ASDs. According to several caregivers who provided public comments to JLARC staff, they were not given any direction about what to do after receiving an ASD diagnosis. One individual at a public input session on ASDs contrasted her experience receiving an ASD diagnosis to receiving a cancer diagnosis, both life-changing events: while physicians who diagnose a person with cancer always provide treatment plans and explain the various options such as chemotherapy and radiology, physicians who diagnose ASDs often share only limited information about different treatment options and their availability.

More than 40 percent of respondents reported not receiving even general information about ASDs from diagnosing clinicians.

As shown in Table 11, respondents to the staff survey of caregivers similarly indicated that the professional who diagnosed their children gave them little information regarding how to access services. More than 40 percent of respondents reported not receiving even general information about ASDs from the person who made the diagnosis. Furthermore, over 90 percent of responding caregivers indicated that healthcare professionals were not useful sources of information.

As described in Chapter 4, the complexity of Virginia's service delivery system makes it difficult for individuals to pursue services, but it also impedes clinicians' ability to make referrals because they may lack easy access to this information. As described in Chapter 4, Virginia's service delivery system lacks a "single point of entry." An additional problem facing diagnosticians is the lack of information about ASD interventions that are deemed scientifically based or promising. As a result, diagnosticians may choose not to discuss the topic.

Table 11: Most Survey Respondents Received Limited Information From Professionals at the Time of Diagnosis

Type of information	Percent of survey respondents who received no information on this topic
General ASD information	42.8%
Educational programs in the area	73.6
Possible interventions	75.9
Other providers in the area	84.7
Local support groups	84.7
Public program in the area	85.7
Effective interventions	85.7
ASD specialists in the area	87.0
Medical programs in the area	93.3
Financial information	97.5

Source: JLARC staff survey of individuals with ASDs and their caregivers, February 2009.

Plans of Care Appear to Center Around Programs Rather Than Individuals With ASDs

Currently, no publicly supported entities are designed to systematically provide comprehensive plans of care for individuals with ASDs. Yet, comprehensive plans of care could be used as a roadmap for these individuals and their caregivers to understand the full array of services needed, determine which publicly supported programs are available to meet these needs, and identify remaining needs that must be addressed with private or other resources. To obtain this service, individuals with ASDs and their caregivers can turn to private or university-based autism clinics which offer comprehensive, multidisciplinary assessments of individuals' needs.

However, even multidisciplinary assessments do not consistently result in detailed plans of care that can be used as blueprints for services. According to interviews with ASD clinic physicians and local Part C staff, ASD clinics sometimes hesitate to specify the types and intensity of services that should be provided, and instead make referrals to the school system or private specialists. As a result, individuals with ASDs may need to consult multiple specialists and obtain multiple, fragmented plans of care which their caregivers must coordinate. This practice is also inconsistent with the management of other medical conditions that require multiple services, such as cancer, for which lead physicians typically oversee all treatments received by their patients.

While all publicly supported programs create individualized service plans, persons with ASDs and their caregivers generally do not receive a single plan of care developed by a professional. Most plans include only services that programs are required and/or able to provide rather than all services from which individuals with ASDs could benefit, regardless of responsibility or funding. Furthermore, the fact that plans of care are designed by program staff appears to foster tension and distrust among some caregivers, who perceive that staff have a vested interest in rationing services in order to limit costs.

OPTIONS TO FACILITATE EARLIER IDENTIFICATION AND DIAGNOSIS OF ASDs IN VIRGINIA

JLARC staff identified options that could facilitate earlier identification and diagnosis of ASDs in Virginia. These options address four main issues that appear to contribute to delayed diagnoses: the need to (1) raise public awareness about child development and ASDs, (2) increase the occurrence of recommended ASD screenings, (3) expedite the diagnostic process by increasing the supply of trained professionals, and (4) improve the information and referrals parents receive once they begin the identification and diagnostic process. The options presented are based on a review of the research literature, interviews with ASD stakeholders in Virginia, and analyses of other states' practices.

Raising Public Awareness Could Help Caregivers Better Identify the Signs of ASDs

A variety of options could be pursued to raise awareness of the "red flags" of ASDs, and what actions to take if children display these signs, by making accurate information readily available. While these options all have merit, there are advantages and disadvantages with each one (Table 12). Several entities, including the Centers for Disease Control and Prevention (CDC) and First Signs, a non-profit organization, have already developed materials to raise public awareness. These materials could potentially be used in any efforts undertaken in the Commonwealth. It should be noted that it can be difficult to gauge the results of awareness campaigns. The two options described below, for example, have been implemented in a few states, but measuring their effectiveness in terms of facilitating earlier diagnoses is difficult because any changes that these states experienced could be attributed to multiple factors.

Information Could Be Distributed to Parents. One option to raise awareness of developmental milestones and the early signs of ASDs is to distribute information to all parents of young children. Rather than undertaking a broad educational effort, this approach would target just those families with a young child. For example,

Table 12: Advantages and Disadvantages of Options to Raise Public Awareness of ASDs

Options	Advantages	Disadvantages
Distribute Information to Parents		
Mail information packets to all parents of children under 36 months	Targets only individuals who require information	Requires creating mailing list for packets
Distribute information packets to parents of young children via physicians' offices and local health departments	Targets only individuals who require information Requires readily available lists of offices and health departments	Fails to reach all individuals who need information
Create a website with basic information about development and the early signs of ASDs	Does not require visiting a physician's office or health department	Duplicates already existing websites, such as CDC or Autism Speaks Necessitates that individuals seek out information Requires Internet access
Launch a Public Awareness Campaign		
Develop and air public service announcements on television and radio	Reaches a wide audience	Duplicates efforts undertaken by other organizations, such as Autism Speaks or CDC Conveys only a small amount of information Is difficult to effectively target
Develop and distribute posters to physician offices and child care centers	Reaches a wide audience	Duplicates efforts undertaken by other organizations, such as Autism Speaks, CDC, and First Signs Conveys only a small amount of information

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

the Commonwealth may decide to develop information packets which could be distributed to all parents of children under age three. The packets could be distributed through direct mailings, which would ensure that all parents receive the information, or be distributed through physician offices and local health departments. The packets could describe developmental milestones, stress the importance of observing a child's development, and advise parents on how to seek professional help if development appears delayed or atypical. Pennsylvania and New Jersey both worked with First Signs, a national organization with public outreach experience, to develop and distribute these types of packets to parents. For instance, New Jersey sent an information mailing to 90,000 parents of children between the ages of 12 and 24 months.

Another alternative would be to create a website with information regarding child development and ASDs, which could include a short questionnaire for parents to complete regarding their own child's development. Ohio's Department of Health, in partnership with the Ohio American Academy of Pediatrics (AAP) chapter, has developed and initiated its own multi-faceted program to facilitate earlier diagnoses, which includes such a website. The information about ASDs and child development is provided by links to the CDC and First Signs websites. The website also contains a list of local providers who conduct developmental screenings and evaluations.

Launch a Public Awareness Campaign. Another option to raise awareness of ASDs, early signs, and the importance of screening among the general public might be to conduct a public awareness campaign. This strategy could involve multiple activities including public service announcements (PSAs), which could be developed and aired on local radio and television stations, and posters, which could be distributed to physicians and child care centers. One major advantage of this strategy is that accurate information would be provided to the general public. To implement this option, Virginia could adopt and customize materials that have already been developed by the CDC (including fact sheets, growth charts, and posters) for its "Learn the Signs. Act Early" campaign. A few states, such as Delaware, Minnesota, and Pennsylvania, opted to work with First Signs to implement public awareness campaigns. Minnesota, for example, partnered with First Signs to develop a press campaign, PSAs, and a hotline to call for referrals or support.

Increasing Consistent and Standardized ASD Screening Among Young Children

To increase the likelihood that young children receive appropriate developmental and ASD-specific screenings, training could be offered to physicians as well as non-medical professionals. Consistent and standardized screening could help Virginians begin early intervention services and receive definitive ASD diagnoses at younger ages, thereby increasing their ability to attain their potential. Table 13 summarizes the major advantages and disadvantages of the various strategies that Virginia could use.

Educate Physicians About Screening. One option to increase the number of physicians who conduct regular and standardized ASD screenings is to engage in a proactive education effort. A variety of approaches could be utilized to propagate information about screening to physicians, including live training courses, the distribution of screening kits, grand rounds at hospitals (lectures or workshops within the hospital setting, which are designed to enhance practitioners' knowledge or improve patient care), or an interactive website. Any of these training options could be combined with the provision of continuing medical education (CME) credits

Table 13: Advantages and Disadvantages of Options to Increase Consistent and Standardized Screening

Options	Advantages	Disadvantages
Train physicians		
Website	Reaches a wide audience Eliminates schedule and location as barriers to participation	Requires Internet access Duplicates materials available from other sources, such as the AAP
Live sessions	Provides interactive information Attracts attendees committed to changing practice	Presents barriers to attendance in the form of location and schedule Requires recruiting knowledgeable instructors
Train-the-trainer workshops	Engages local community resources to train others Builds on existing infrastructure and relationships Requires few resources	Necessitates committed individual trainers Is inconsistently offered across the State
Train non-medical personnel		
Website	Reaches a wide audience Eliminates schedule and location as barriers to participation	Requires Internet access
Live sessions	Provides interactive information Attracts attendees committed to changing practice	Presents barriers to attendance in the form of location and schedule Requires recruiting knowledgeable instructors

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

for participation, which would provide physicians with an incentive to learn about screening.

Providing physicians with training on screening can be a relatively low cost activity, with the potential for impact if physicians change their practices. However, the extent to which physicians will be willing and able to change their practices based on a one-time training session may be linked to addressing other major issues such as reimbursement. As discussed earlier, one of the primary barriers to performing screening is that physicians face difficulty in receiving reimbursement for these services; to overcome this issue, training could include information about how to most effectively bill insurance companies for screening services.

Many states have initiated projects to increase physician knowledge about ASDs and screening practices. California, for instance, has developed an interactive education website that provides information about developmental disorders, early signs, and screening methods to medical professionals. The website allows medical professionals to register and receive CME credits for reading the information and taking a short post-test. However, California has not measured how, if at all, this website has changed physicians' screening practices.

Ohio's Department of Health, in partnership with the Ohio AAP chapter, has also developed and initiated its own multi-faceted program to facilitate earlier diagnoses. One component of this project involved providing two-day training sessions to medical professionals on screening. In the pilot for this project, 28 pediatric practices participated in the training sessions. Before participating in the workshops, these practices conducted developmental screenings on 15 percent of the children seen for the 24-month well-child check-up. One month after participating in the workshop, the practices conducted developmental screenings on 39 percent of the children seen for 24-month well-child check-ups, a 24 percentage point increase. While the training appears to have improved these physicians' screening practices, it still falls short of Ohio's goal to screen 90 percent of children seen at 24-month well-child check-ups. Additionally, it should be noted that the 28 practices that participated in this training pilot project were the most eager to improve ASD screening practices.

Rather than develop their own training programs, as did California and Ohio, many states have partnered with a national organization with experience in providing training on ASDs. For example, at least seven states (Alabama, Delaware, Minnesota, Ohio, Pennsylvania, Texas, and Wisconsin) have partnered with First Signs to offer training to medical professionals. Minnesota appears to have the most success with the program due to the involvement of early intervention staff.

Minnesota Works With First Signs to Raise Awareness and Train Screeners

Minnesota's Department of Education (DOE) partnered with First Signs to implement a two-year project. The project involved a variety of activities including launching a press campaign, sending information to 4,000 medical and early childhood professionals, offering three workshops and two grand rounds sessions for medical professionals, offering three "train-the-trainer" workshops for early intervention and autism specialists, and providing a webcast session. Over two years, more than 1,100 medical professionals participated in these sessions. Notably, the "train-the-trainer" workshops were attended by 130 professionals who within one year trained 685 medical professionals and 3,238 early childhood professionals in their own communities.

Train Non-Medical Personnel to Conduct Screenings. Another option to increase the number of children screened for ASDs would be to expand the number of people performing screenings by relying upon non-medical personnel, such as daycare workers, preschool teachers, early intervention specialists, or social workers. Some of the states that have partnered with First Signs, such as Minnesota and Pennsylvania, have included Early Intervention Part C personnel in training sessions. Connecticut has trained its Early Intervention Part C personnel to perform ASD screenings, and they now screen every child seen at intake.

Although Ohio does not train non-medical personnel to conduct developmental screenings, the state encourages early child care and day care programs to conduct developmental screenings through the "Step Up to Quality" program, which is a tiered quality rating system with benchmarks above and beyond the state's minimum health and safety licensing standards. To attain the program's two highest levels, child care centers must conduct developmental screenings within 60 days of a child's enrollment and make any needed referrals based on those screenings within 90 days. In the program's first year, 184 child care centers (approximately two percent of the state's regulated child care centers, which enroll nearly 16,000 children) achieved the two highest levels.

Expediting Diagnoses of ASDs

To minimize delays which parents experience when pursuing an ASD diagnosis, Virginia could explore several options to develop greater diagnostic capacity throughout the Commonwealth. Each option has positive and negative considerations, as displayed in Table 14.

Train Pediatricians to Make ASD Diagnoses. Although the AAP and pediatricians interviewed by JLARC staff indicated that pediatric-

Table 14: Advantages and Disadvantages of Options to Expedite ASD Diagnoses

Options	Advantages	Disadvantages
Train Pediatricians to Make Diagnoses		
Pediatricians trained in making ASD diagnoses in straight forward cases	Reduces the number of individuals referred to overburdened specialists and multidisciplinary teams	Does not deliver a multidisciplinary evaluation May lead to over-diagnosis
Create Regional Capacity to Provide Multidisciplinary Diagnoses		
Multidisciplinary diagnostic teams housed in local school districts	Is available throughout the State Provides care and intervention plans that reflect community resources Streamlines the diagnostic process	May be perceived by caretakers as developing limited plans of care because the school provides some services
Expanded university-based clinics	Delivers comprehensive evaluations Provides impartial plans of care that reflect needed rather than available services	May not be available in many parts of the State May not account for availability of community resources for plans of care Complicates state oversight of activities since it is a university setting Adds an additional organization to ASD service delivery system
Expanded role of child development clinics	Delivers comprehensive evaluations Provides impartial plans of care that reflect needed rather than available services	Requires recruiting speech and occupational therapists Necessitates additional ASD training for personnel Is limited to nine locations
Multidisciplinary diagnostic teams housed in local community services boards (CSBs)	Is available throughout the State Provides care and intervention plans that reflect community resources	Adds an additional organization to the State's ASD service delivery system Presents a potential conflict of interest since CSBs also provide some services Requires re-focusing on developmental disabilities, rather than intellectual disabilities

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

ians are capable of diagnosing straightforward ASD cases without referring to specialists, this practice seldom occurs in Virginia. One approach to increasing the Commonwealth's diagnostic capacity might be to sponsor workshops that would train pediatricians to identify and diagnose ASDs in simple cases. According to the AAP, most pediatricians already have the knowledge needed to provide these diagnoses. As a result, workshops would likely need to focus on appropriate diagnostic assessment instruments, referrals, and care management. While this approach would reserve the use of specialists and multidisciplinary teams for the most complex cases, it may not be optimal because it is not a multidisciplinary evaluation that is recommended for all individuals with ASDs. Additionally, it is unclear how many ASD cases are "straight forward" and would be diagnosed by pediatricians; thus, the extent to which this effort would increase the Commonwealth's diagnostic capacity is unclear.

Create Regional Capacity to Provide Multidisciplinary Diagnoses. Another option to increase the Commonwealth's diagnostic capacity is to develop regional multidisciplinary teams. A variety of initiatives already existing in the Commonwealth could be expanded to provide greater diagnostic capacity, including leveraging school-based teams, university-based clinics, Department of Health's (VDH) child development clinics (CDCs), or community services boards (CSBs). Regardless of where the teams would ultimately be housed, this option would involve recruiting, training, and retaining a team of professionals from different disciplines to provide diagnostic services to a designated region. The professionals involved in the team might include a general pediatrician, nurse, psychologist, social worker, developmental pediatrician, neurologist, and educational consultant, among others. As described in Chapter 4, these venues could also be used to provide case management services to individuals with ASDs. If exercised, these options would provide parents a single point of services where they could both obtain a diagnosis and be assigned to a case manager responsible for overseeing their care.

Ohio Established Regional Multidisciplinary Teams

As part of its multifaceted initiative to facilitate earlier diagnoses, Ohio has increased regional diagnostic capacity by training and establishing multidisciplinary teams. In the fall of 2008, the Ohio chapter of the AAP provided training to teams from five different counties. Each team consisted of a local pediatrician, Part C professional, a professional from the local mental retardation and developmental disabilities agency, and an education consultant from the local school district. These teams were trained to provide standardized, comprehensive assessments.

One potential venue for a regional multidisciplinary diagnostic team would be local school districts, because schools are already involved in assessing children for ASDs as part of the eligibility process for special education services. Commonwealth Autism Service (CAS) has arranged for one regional school program in Virginia to create diagnostic teams: Virginia Treatment Clinic for Children at Virginia Commonwealth University, which is funded by CAS, is training two multidisciplinary teams for the Shenandoah Valley Regional Program. The teams will provide comprehensive ASD diagnostic assessments in a region that does not currently have that capacity. Discussions are underway to expand this approach to other school divisions.

A second potential venue would be building greater capacity in existing university clinics. The University of Virginia (UVA) and VCU medical centers both have developmental clinics that provide diagnostic services to a large number of children from all parts of the State. These clinics could be expanded to serve more children, and they could be supplemented by satellite locations to provide greater geographic coverage. For example, North Carolina's Division TEACCH, administered by the University of North Carolina, offers diagnostic evaluations to anyone with a suspected ASD at nine regional centers in addition to its Chapel Hill location.

A third potential venue would be to house regional multidisciplinary diagnostic teams in the nine child development clinics (CDCs) operated by VDH. The CDC network, which is already at capacity, could be expanded to handle more cases and increase its coverage of the State. However, additional training and qualified staff may be needed to conduct more ASD assessments. While CDCs report an increased number of referrals for ASD assessments, they still conduct a relatively low number of ASD diagnoses. In addition, not all CDCs have staff trained in conducting ASD assessments, and none retains the services of speech or occupational therapists.

A final potential venue to house multidisciplinary teams would be community services boards (CSBs). This option would integrate the service delivery system for individuals with ASDs because 33 of Virginia's 40 Early Intervention Part C offices are co-located with CSBs. Additionally, the Department of Behavioral Health and Developmental Services, which will become responsible for overseeing the State's developmental disabilities system on July 1, 2009, contracts with the CSBs to provide services and is also the designated lead agency for Virginia's Early Intervention Part C program. Developing and locating regional multidisciplinary diagnostic teams in CSBs would increase the Commonwealth's diagnostic capacity, as well as streamline the referral process because many local Part C offices are co-located with CSBs.

Improving the Information and Referral Process

The following options would increase the consistency with which parents receive the necessary referrals and information during the identification and diagnosis process. These options would require varying levels of resources and have different degrees of impact on the referral process as illustrated in Table 15.

Provide Additional Information to Parents. As described in Chapter 4, the State could create a website containing information about ASDs, effective interventions, and local service providers. While this tool could be used by physicians to guide parents toward appropriate interventions and providers, a section targeted at health

Table 15: Advantages and Disadvantages of Options to Improve the Referral Process

Options	Advantages	Disadvantages
Provide Additional Information to Parents		
Provider section in informational website	Reaches a wide array of providers Provides consistent and accurate information to individuals at the time of diagnosis Contains information on local resources	Require computer and internet access Does not guarantee use by medical professionals
Early Intervention Part C referral cards	Increases chances of children receiving referrals to Early Intervention Part C Ensures that parents receive contact information about Early Intervention Part C	Does not guarantee distribution to patients Does not guarantee that families will follow-up
New diagnosis information packets	Provides consistent and accurate information to individuals at the time of diagnosis Contains information on local resources	Duplicates materials provided by other organizations Does not guarantee distribution to parents
Create Comprehensive Plans of Care		
Guidelines for providers who conduct multidisciplinary assessments	Provide impartial plans of care that reflect needed rather than available services Uses existing expertise	Does not compel the use of guidelines Is limited by State's capacity Does not consider available community resources
Expanded scope of Early Intervention Part C / School Part B assessments	Builds upon existing process	May be viewed as biased/trying to limit costs Requires knowledge about other disciplines and community resources
Regional offices conduct multidisciplinary assessments	Provides impartial plans of care that reflect needed rather than available services Could integrate with regional case management and diagnosis Expands system capacity Provides statewide access to services	Requires ramp-up in knowledge and resources

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

care professionals could also be created. A section tailored to professionals' needs and expertise could place greater emphasis on the research literature that may not be accessible to lay persons. In addition, this tool could be used to provide training and education to physicians as described earlier in this chapter.

Another option to improve the referral process is to develop information that physicians could distribute to their patients when an ASD or suspected ASD is identified. To this end, the Commonwealth could distribute Early Intervention Part C referral cards that physicians could give to the parent of any child with an abnormal screening. This referral card would ensure that physicians advise parents to contact local Part C offices, and would also provide parents with the information necessary to contact them. The California North Bay Regional Center distributes cards that contain a brief ASD screening instrument and the center's contact information to local pediatricians, family physicians, and other practitioners. This card serves to both inform individuals about what to look for and whom to contact if a child displays any of signs of ASDs.

Similarly, physicians could give parents an information packet for newly diagnosed children, such as the toolkit that was described as an option in Chapter 4. Tools have already been created by national advocacy groups (such as Autism Speaks' "First 100 Days" kit) and other states, and could be tailored by Virginia to include basic information about ASDs, services provided by the State, and referrals to local resources and providers. Although providing materials to physicians does not guarantee that they will distribute them, it increases the likelihood that parents will receive appropriate and useful information as soon as their child enters the identification and diagnosis process.

Outreach Efforts Help Facilitate Earlier Diagnoses in California

California's North Bay Regional Center collaborated with local school districts and private practice clinicians to establish two one-stop diagnostic clinics where regional center and school staff work together to perform comprehensive ASD evaluations and coordinate services. The collaborative also developed and disseminated cards containing a screening instrument and referral information to local practitioners. During the first year of the program, the age of ASD diagnosis in the three-county area dropped from 38 to 34 months.

Create Comprehensive Plans of Care. In order to provide individuals with ASDs and their parents with person-centered and comprehensive plans of care, Virginia could issue service guidelines to providers who conduct multidisciplinary assessments and encourage them to make specific referrals needed to fully address their needs. In particular, specialists involved in the assessment could provide specific guidance about the types, intensity, and frequency of therapies required by an individual in order to address the full range of their symptoms. The plan of care could also include information about Virginia programs that provide each service, as well as the names of private providers available as an alternative. While this approach would be low-cost to the State, it may not be far-reaching: as described previously, only eight percent of diagnoses were performed by a multidisciplinary team, according to the JLARC staff survey of individuals with ASDs and their caregivers. Furthermore, private providers may choose not to follow guidelines unless given an incentive to do so.

As an alternative, the State could expand the scope of existing individualized plans to include all aspects of an individual's care and all providers. For example, teams that conduct educational assessments to determine eligibility for School Part B services and the scope of individualized educational programs could be tasked with creating comprehensive plans of care that not only capture the services that schools are required to provide under federal law, but also identify all other services that are needed to address all areas of functioning. This approach would only help Virginians who are enrolled in publicly supported programs that create individualized plans, including the Early Intervention Part C, School Part B, Vocational Rehabilitation, and waiver programs. Furthermore, plans of care created by program staff may not be viewed as impartial.

Lastly, Virginia could task regional diagnostic resources described in the previous section, such as Child Development Clinics or CSBs, to also design comprehensive plans of care. One of the advantages of this option would be to integrate the delivery of services into one entity which could serve as a single point of entry.

Summary of Options to Facilitate Earlier Identification and Diagnosis of ASDs

In addition to having different policy merits, options described in this chapter vary in terms of the financial and human resources required, the extent to which they address the issues discussed in this chapter, and the time needed for implementation. Figure 11 summarizes these implementation considerations and reflects the best judgment of JLARC staff based on discussions with experts and knowledge gained during this review. To facilitate the State's decision whether and how to facilitate earlier identification and diagnosis of ASDs, the Department of Behavioral Health and Developmental Services (BHDS) should collaborate with relevant stakeholders to weigh policy and implementation considerations, and identify which options are most suitable to raise public awareness about ASDs, increase consistent and standardized screenings, expedite diagnoses, and improve the referral process in Virginia. Specifically, BHDS should collaborate at a minimum with individuals with ASDs, caregivers, the State departments of Health and Education, Virginia universities, and the Virginia chapter of the American Academy of Pediatrics.

Recommendation (3). The Department of Behavioral Health and Developmental Services should collaborate with relevant stakeholders to (1) evaluate the options for raising public awareness about autism spectrum disorders, increasing consistent and standardized screenings, expediting diagnoses, and improving the referral process; and (2) identify no later than March 31, 2010, which, if any, options are most beneficial to pursue.

Figure 11: Implementation Considerations for Options to Facilitate Earlier Identification and Diagnosis

Major Goal	Resources Needed	Extent to Which Addresses Major Goal [a]	Time Needed to Implement
Raising Public Awareness About ASDs			
Information Distributed to Parents	↓	★★	🕒🕒
Public Awareness Campaign	↓	★	🕒🕒
Increasing Consistent and Standardized Screening			
Physician Training			
Website	↓	★	🕒
Live sessions	↓	★★	🕒🕒
Train-the-trainer workshops	↓	★★★	🕒🕒
Training for Non-Medical Personnel			
Website	↓	★	🕒
Live sessions	↓	★★	🕒🕒
Expediting Diagnoses of ASDs			
Pediatricians Trained to Make Diagnoses	↓	★★	🕒🕒
Regional Capacity to Provide Multidisciplinary Diagnoses	↓		
Local school districts	↓	★★★	🕒🕒🕒
University clinics	↓	★★★	🕒🕒🕒
VDH's child development clinic network	↓	★★★	🕒🕒🕒
Community services boards	↓	★★★	🕒🕒🕒
Improving the Information and Referral Process			
Additional Information Provided to Parents			
Early Intervention Part C referral cards	↓	★★	🕒
New diagnosis information packets	↓	★★	🕒
Provider section in informational website	↓	★★	🕒🕒
Comprehensive Plans of Care	↓		
Guidelines for providers who conduct multidisciplinary assessments	↓	★	🕒
Expanded scope of Early Intervention Part C/School Part B assessments	↓	★★	🕒🕒
Regional offices conduct multidisciplinary assessments	↓	★★★	🕒🕒🕒

Least ↓ Most

★ Somewhat
★★ Substantially
★★★ Greatly

🕒 < 6 Months
🕒🕒 6-18 Months
🕒🕒🕒 > 18 Months

[a] Ratings reflect the extent to which each option addresses the major goal described in the gray-shaded row.

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

Chapter 6

Enhancing the Early Intervention System for Children With Autism Spectrum Disorders

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In Summary

The literature on ASDs consistently identifies certain key components that should be included in early intervention programs serving young children with ASDs, yet the Virginia programs with primary responsibility for serving this population do not consistently contain these components. Additional services funded through Medicaid may also not consistently address the needs of young children with ASDs, mostly due to lack of family knowledge and provider qualifications. In order to improve the early intervention system for young children with ASDs, Virginia could consider a range of options, including increasing the knowledge and qualifications of providers serving young children with ASDs, increasing resources for early intervention and preschool programs, developing a new waiver specifically for individuals with ASDs, and utilizing regional offices such as community services boards for delivering services.

For years, both the U.S. Congress and the Virginia General Assembly have recognized the importance of early intervention so that children with or at risk of a disability have the opportunity to reach their greatest level of functioning. In 1975, Congress passed legislation (the Education for the Handicapped Act, now the Individuals with Disabilities Education Act or IDEA) requiring states and localities to provide educational services to children with disabilities ages three and over. Congress amended the federal law in 1986 to extend services to children beginning at birth after finding an "urgent and substantial need" to enhance the development of very young children with disabilities and minimize the potential delays for those at risk.

Virginia has followed Congress's lead and implemented State and local programs to ensure services are provided as required by federal law. The programs most directly targeting young children with ASDs include the Early Intervention Part C program for infants and toddlers ages birth through two (also known as the Infant and Toddler Connection), and School Part B special education services for children ages two through five. In addition to the Part B and C programs, eligible young Virginians with ASDs can access early intervention services that are funded by the Medicaid program.

Chapter Research Methods

JLARC staff interviewed a variety of stakeholders, including staff from the Faison School for Autism in Richmond; Virginia Commonwealth University; departments of Health, Behavioral Health and Developmental Services (formerly DMHMRSAS); and Medical Assistance Services; personnel at eight local Early Intervention Part C offices; and special education staff at eight school divisions. Staff surveyed a random sample of 560 public schools and achieved a response rate of 78 percent. Of the 436 responding schools, 380 had students with autism or suspected autism. Additionally, staff conducted an extensive review of the research literature and practices used in other states. Additional details on study methods are included in Appendix B.

INTENSIVE EARLY INTERVENTION SERVICES CAN IMPROVE OUTCOMES FOR CHILDREN WITH ASDs

The research literature consistently indicates that providing intensive services at an early age is the most effective means of achieving normal or near-normal functioning among individuals with ASDs. As discussed in Chapter 2, multiple studies have found that children with ASDs who participate in early intensive behavioral interventions (EIBI) experience functional improvements and incur lower special education costs, whereas those who did not receive EIBI tend to participate in publicly funded programs for much of their lives. In addition to being intensive in terms of hours and duration, EIBI programs contain several components that are key to their effectiveness, such as a structured environment and an ASD-specific curriculum.

Although most studies of EIBI focused largely on children with ASDs over age three, recent studies have also shown promising results for children under age three. A 2001 study found a positive correlation between the number of hours of speech therapy received by children with ASDs between the ages of two and three and their language skills at age four; another study showed a substantial increase (from 36 to 82 percent) in the percentage of children who began to speak after beginning an intensive program at age two.

There may be several reasons why children with ASDs who begin treatment at a young age may have the best outcomes. According to child development literature, early experiences play a critical role in shaping brain function. Young children may have greater brain plasticity (ability of the brain to change itself as a result of experience) and can acquire skills more quickly and easily than older children. For example, learning a second language at an early age requires much less effort than learning another language at an older age. In addition, an early start to treatment may result in better outcomes because it is easier to teach children with ASDs appropriate behaviors before they learn inappropriate ones than to both correct inappropriate behaviors and teach appropriate ones at the same time, according to one expert interviewed by JLARC staff. For example, children with ASDs often exhibit repetitive behaviors such as arm flapping or spinning - these behaviors serve as an adaptive function, particularly if children lack the ability to communicate their wants or fears. Over time, these behaviors may become conditioned if they are reinforced by the child gaining adult attention or escaping from an undesired situation.

EFFECTIVE AND EFFICIENT EARLY INTERVENTION PROGRAMS CONTAIN MULTIPLE COMPONENTS

According to the research literature, certain characteristics are present in effective early intervention programs serving children with ASDs, although their specific teaching methods may differ. While experts have differed somewhat on the importance of certain components, most agree on several characteristics that are key to effectiveness:

- family involvement;
- individualization of services;
- intensity of intervention in social and nonsocial environments for at least 20 to 25 hours per week (for ages three and older) for two to three years;
- interventions at early ages;
- specialized curriculum designed to address deficits in skills children with ASDs often experience;
- structured environments that are predictable, follow routines, and have low child-to-staff ratios to facilitate acquisition of skills but designed for supports to fade as skills are acquired; and
- systematic instruction based on conceptual or theoretical framework for teaching children with ASDs and adjusted based on data pertaining to child progress.

Moreover, these elements were identified by the National Research Council (NRC) as critical features for preschool programs for young children with ASDs. Appendix E provides further description of these components.

In addition to the characteristics that define effective early intervention programs for young children with ASDs, the following general measures should also be taken to ensure their efficiency and effectiveness:

- providing interventions that are research-based,
- using qualified staff and other providers, and
- assessing program outcomes.

In addition to being well-accepted quality assurance measures for publicly funded programs, the IDEA legislation that governs the provision of early intervention and special education services to young children with disabilities specifically requires states and localities to include these three general quality measures in their programs.

VIRGINIA EARLY INTERVENTION PROGRAMS DO NOT CONSISTENTLY EMPHASIZE EFFECTIVE COMPONENTS FOR SERVING CHILDREN WITH ASDs

Virginia's programs serving young children with ASDs typically do not reflect all components that have been found to be most effective (Figure 12). This can occur either because programs are not designed to emphasize an effective component, or an effective component is not consistently implemented despite program emphasis. While federal requirements may preclude Virginia from changing a program's emphasis to incorporate effective practices, the State could address areas in which programs struggle to consistently comply with required practices. It is important to note that strong adherence to a particular component does not mean that improvements are not needed in that area. For example, while Virginia's Part C program adheres strongly to the family involvement component, over 42 percent of caregivers who responded to a JLARC survey indicated that they did not receive adequate training from Part C providers.

Part C Program Does Not Consistently Implement Most Components of Effective Programs for Young Children With ASDs

Virginia's Part C services appear to emphasize and consistently utilize only two of seven components of effective early intervention programs for children with ASDs.

Virginia's Part C services, which are provided by 40 local Part C programs, appear to emphasize and consistently utilize only two of seven components of effective early intervention programs for children with ASDs: family involvement and individualization of services (Figure 12). As a result, the outcomes of the infants and toddlers with ASDs who receive these services may not be maximized. In fact, 57 percent of caregivers who responded to the JLARC staff survey indicated that Part C services their children with ASDs received did not result in meaningful improvements. In addition, between one-third to one-half of caregivers rated the impact of Part C services on their child's functional needs as poor (Figure 13), and only 19 percent indicated that Part C services reduced the amount of special education that their child would otherwise have needed upon entering school.

Intensive Service Provision Is Not Fundamental Component of Coaching Model Used by Virginia's Part C System. Infants and toddlers with ASDs typically do not appear to receive services that are sufficiently intensive from Virginia's Part C system. Almost all (96 percent) caregivers who responded to the JLARC staff survey reported that their children received three or fewer hours of interventions per week from Part C providers which most (87 percent) indicated was insufficient to meet their child's needs. In addition, local Part C staff interviewed during site visits reported providing

Figure 12: Early Intervention Programs Serving Virginia Children with ASDs Do Not Consistently Emphasize Key Components of Effective Programs

	Component	Implementation Part C	Implementation Part B Preschool-Age
Effective Early Intervention Programs For Young Children with ASDs	Family involvement	●	○
	Individualization of services	●	●
	Intensity of intervention	○	○
	Interventions at early ages	🔵	●
	Specialized curriculum	🔵	🔵
	Structured environment	○	🔵
	Systematic instruction	🔵	🔵
General Effective Practices	Research-based interventions	🔵	🔵
	Qualified personnel	🔵	🔵
	Outcome measurement	🔵	🔵

Legend

In terms of its benefit to young children with ASDs, this component is

● Strong - emphasized by program and generally implemented

🔵 Inconsistent – emphasized by program but not always implemented

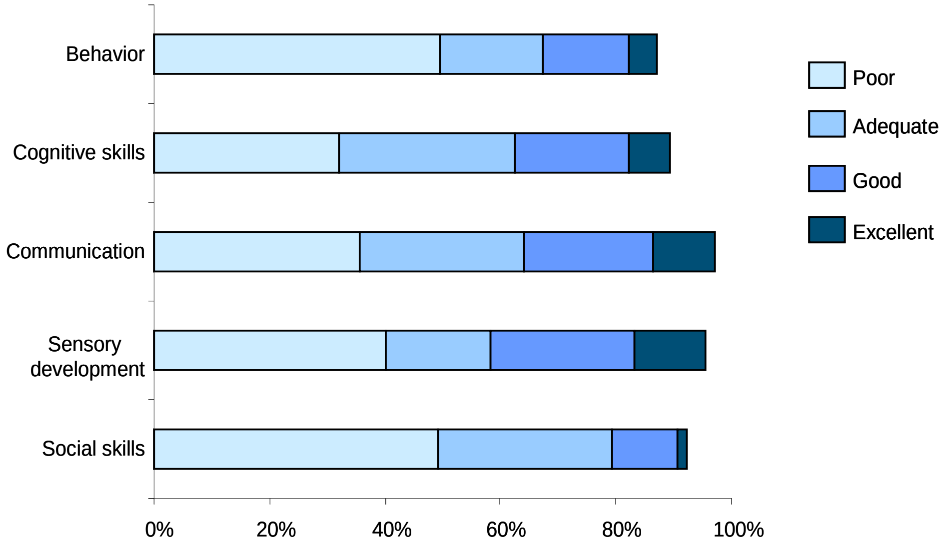
○ Weak – not emphasized by program and generally not implemented

Note: See Appendix E for further explanation of program ratings.

Source: JLARC staff analysis of State and federal regulations, interviews with program staff, and results from the JLARC staff survey of a sample of Virginia public schools and individuals with ASDs and their caregivers, February 2009.

services to infants and toddlers with ASDs from one hour every other week to two hours per week, on average. Infants and toddlers enrolled in the Part C program typically receive few hours of interventions directly from Part C providers because Virginia's program, similar to that of many states, follows what is known as the "coaching model" of service delivery. This model is strongly aligned with federal Part C regulations, and the early intervention literature suggests that it can lead to gains in child development and improve parents' feelings of competence in meeting their child's needs. According to a Virginia Part C guidance document, the service provider in Virginia serves as a consultant or coach to the parent rather than having a primary focus on providing services to the infant or toddler directly. Even though

Figure 13: At Least One-Third of Caregiver Survey Respondents Rated Impact of Part C Services on Child's Functioning As Poor



Note: Responses are from caregivers of children with ASDs who are receiving Part C services or received them within the past three years. Responses of "not sure" are not included in the figure so results may not sum to 100 percent.

Source: JLARC staff survey of individuals with ASDs and their caregivers, February 2009.

parents may be providing interventions to their child beyond time spent working with providers, Part C staff explained that some parents lack the skills or abilities to work intensively with their children. However, results of a recent study investigating the effectiveness of the coaching model for infants and toddlers with ASDs suggests that parents can meaningfully provide intensive and active engagement if they are able to successfully learn and apply the interventions.

Part C System Emphasizes Natural Rather Than Structured Environments. Federal and Part C documents emphasize that the majority of services are to be delivered in natural environments such as the home or community settings in which other children without disabilities participate. The natural environments criterion was emphasized in the reauthorization of Part C of IDEA in 1998 based on research indicating that interventions are most effective when integrated into the child's daily activities and routines. However, the ASD literature recommends that services be provided to young children with ASDs in highly structured environments. In particular, activities should be predictable and routine since children with ASDs do not respond well to change, and few distractions should be present to assist providers in getting children to attend or pay attention. While a natural environment can also be highly structured, the burden of creating a structured environment is ultimately placed on parents, day care providers, and other caregivers who may lack the tools or resources to achieve such structure.

Few Part C Programs Appear to Provide Research-Based Interventions to Infants and Toddlers With ASDs. Local Part C program staff reported during site visits that most infants and toddlers with ASDs are receiving speech and occupational therapies, which are generally accepted as effective practices for serving this population, but few reported providing ASD-specific interventions that are considered research-based, as recommended by IDEA. For example, one local program visited by JLARC staff reported they had, at one time, been able to provide ABA-based interventions to infants and toddlers with ASDs using students at a local university, but they were no longer able to provide this level of service. No other programs reported using research-based interventions, but two reported using Floortime, which has limited supporting evidence as discussed in Chapter 2. Furthermore, caregivers who responded to the JLARC staff survey indicated that only six percent of young children received behavioral modifications or ABA-based therapies through the Part C program.

One reason that local Part C programs do not offer a greater level of effective ASD-specific interventions may be due to the lack of consistent training in serving infants and toddlers with ASDs. While local Part C staff interviewed by the study team were generally knowledgeable about treating ASDs, they all agreed more information and training was needed. In addition, caregivers of young children who received Part C services indicated that local Part C providers were not sufficiently trained, in their opinion: 49 percent of caregivers indicated that infant educators appeared to lack the necessary experience or training to address the needs of their dependents, and 36 percent reported that related service providers (such as speech or occupational therapists) appeared to lack necessary skills.

According to staff in the State Part C office, training specific to ASDs has historically been limited to seminars within the annual Early Intervention Conference, which is hosted by the State Part C office. In 2008, regional Communities of Practice in Autism (COPA) groups formed to provide training and information to local Part C providers specifically on ASDs. However, these groups are designed to meet the needs of their region rather than provide a consistent level of information and training statewide. Moreover, only one local Part C program visited by JLARC staff has been able to send their infant educators, speech pathologists, and occupational therapists to formal trainings in ASD-specific interventions, but resources to do this were provided by the local community services board rather than the Part C system.

Part C Programs Report Outcome Measures, but Not by Disability. The State Part C office collects information on child progress through two means, but this information is not analyzed or reported by disability. As a result, the State and local Part C programs are lacking quantitative information to gauge how well infants and toddlers with ASDs are being served overall and within each local Part C program. When IDEA was reauthorized in 2004, state Part C programs were required to report on child outcome measures in three domains: (1) positive social-emotional skills, including social relationships; (2) acquisition and use of knowledge and skills, including early language/communication skills; and (3) use of appropriate behaviors to meet their needs. However, states are only required to report this information across all infants and toddlers served, rather than by disability category. In addition, families of infants and toddlers who receive Part C services are asked to complete a family satisfaction survey in which they are asked to rate the adequacy of services and the progress they think their child has made. Results cannot be assessed by disability because a question on disability is not included on the survey.

Part B Services for Young Children with ASDs

While school divisions can provide a variety of special education services to children ages two to five with ASDs, this chapter focuses mostly on services provided in special education preschool classrooms, as it is the setting in which schools that responded to the JLARC survey reported serving most (70 percent) young children with ASDs.

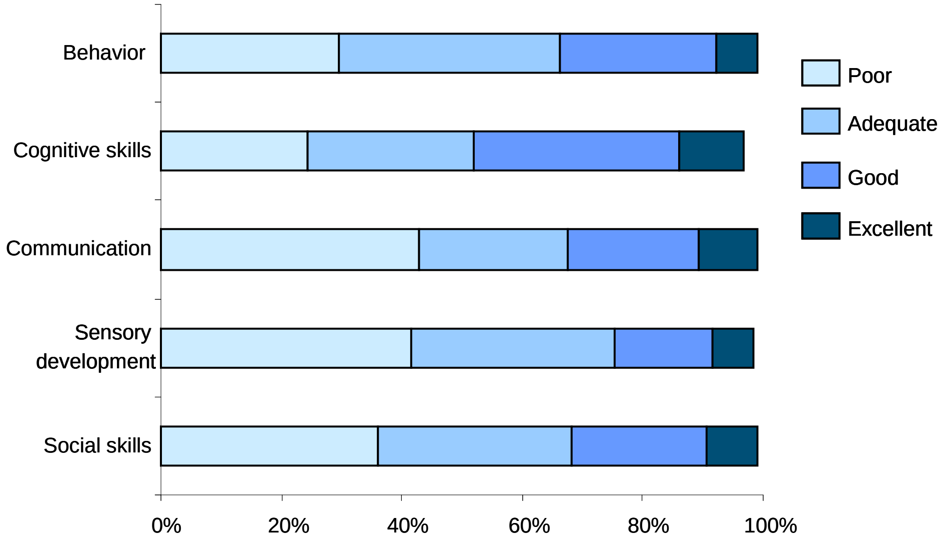
School Part B Services Offer Structured Environments, but Do Not Consistently Provide Intensity and Research-Based Interventions

Special education preschool programs for students with ASDs do not consistently implement several components of effective programs for young children with ASDs. In particular, preschool programs may lack the intensity and family focus recommended by the literature (Figure 12). In addition, preschool programs for children with ASDs do not consistently use scientifically based or promising practices, employ staff that are trained in ASD interventions, or measure progress. These factors may explain, in part, why Virginia's public schools face challenges in serving preschool-age children with ASDs and are sometimes unable to effectively provide services to improve their ability to learn and function in every day life.

Only half of schools reported that they were able to provide most preschool-age children with ASDs the types and intensity of services needed to minimize their need for special education.

In fact, the responses of caregivers and a sample of schools surveyed by JLARC staff appear consistent on this measure. Only half of schools reported that they were able to provide most preschool-age children with ASDs the types and intensity of services needed to minimize their need for special education as they get older. Similarly, only slightly more than 40 percent of caregivers of children with ASDs age five or younger indicated that schools provided either the proper types or intensity of services needed to meet their child's needs. Furthermore, between one quarter and 42 percent of caregivers rated schools' ability to meet the behavioral, cognitive, communication, sensory, or social needs of their preschool-age children as poor (Figure 14).

Figure 14: At Least One-Fourth of Caregivers Rated School's Ability to Improve Child's Functioning As Poor



Note: Responses of "not sure" are not included in the figure so results may not sum to 100 percent.

Source: JLARC staff survey of individuals with ASDs and their caregivers, February 2009.

Preschool Programs Offer Structure but Often Lack Recommended Staffing Ratios. While most schools that responded to the JLARC staff survey reported serving preschool-age children in special education classrooms, they often lack the low child-to-staff ratios that are key to creating a truly structured environment for students with ASDs, as defined in the literature. Access to a structured preschool classroom is one of the benefits of School Part B services for young children with ASDs, according to local Part C program staff, and many families choose to transition their children to preschool after their second birthday as a result. While the literature suggests that programs should offer 1:1 or 2:1 child-to-staff ratios (at least initially), schools that responded to the JLARC staff survey reported that less than four percent of preschool-age children with ASDs received 1:1 instruction. Further, 40 percent of schools with preschool classrooms reported that high child-to-staff ratios were a moderate or significant challenge in their ability to meet the educational needs of students with ASDs. It is important to note that not every child with an ASD may require a low staffing ratio to make meaningful improvements, but those with more severe needs likely do. Because the Virginia Standards of Quality (SOQ) fund staffing ratios of 6:1 (child:staff) or 8:2 (including a paraprofessional) for preschool special education classrooms serving students with ASDs, schools that choose to provide lower staffing ratios are supported largely by local funds.

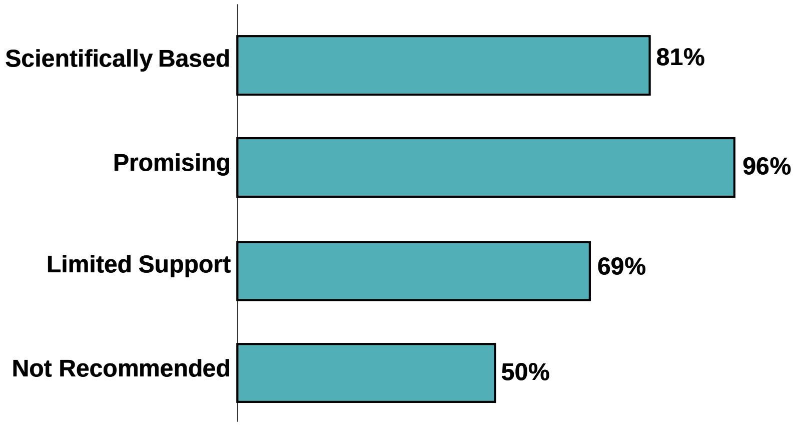
Preschool Programs May Not Be Adequately Specialized to Meet the Needs of Students With ASDs. As mentioned previously, many caregivers who responded to the JLARC staff survey reported schools are poorly addressing the behavioral, cognitive, communication, sensory, and social needs of children with ASDs (Figure 14). In an effort to better address the needs of students with ASDs, some schools have developed classrooms solely for these children; however, schools that responded to a JLARC staff survey reported that only eight percent of preschool-age students are served in these settings. While some school divisions and other ASD stakeholders may discourage the creation of ASD-specific classrooms, it appears these classrooms can be designed and used in a manner that would address these concerns. For example, several school divisions reported not using ASD classrooms because they are considered restrictive settings, but classrooms can be designed to integrate activities with typically developing peers. In addition, stakeholders reported that schools with ASD classrooms may tend to place all children with ASDs in these setting, but special education staff from two school divisions interviewed by JLARC staff reported placing only those students with more intensive needs in them. Additionally, nearly half of schools (48 percent) with preschool programs that responded to the JLARC staff survey reported that insufficient resources to create an ASD classroom was a moderate or significant challenge to meeting the educational needs of students with ASDs. Schools in rural areas most frequently reported insufficient resources to create an ASD classroom as a challenge.

Preschool Programs Do Not Consistently Provide Intensive Services. The majority of schools that reported serving young children with ASDs provide preschool programs for students with developmental disabilities, which is the setting in which schools reported 62 percent of preschool-age children with ASDs are served. However, these programs may not provide at least 20 to 25 hours of active engagement each week, year round, which is recommended by the ASD literature. Results of the JLARC staff survey indicate that fewer than two-thirds of preschool programs for students with developmental disabilities have full-day classes, with great regional variation. In particular, fewer than half of special education preschool classrooms for students with developmental disabilities in the Tidewater, Northern Virginia, and greater Fredericksburg areas are full time (see Appendix E for map of areas). Though young children with ASDs may have access to a full-day classroom outside of the school division's preschool program, this does not appear to occur frequently. Approximately 46 children with ASDs and 720 with developmental delay were served by Head Start in 2006-2007, based on the program's annual report. Approximately six percent of preschool-age students with ASDs received services in separate special education centers in 2005-2006, according to DOE. In addition, 11 percent of preschool-age students with ASDs received in-home services, based on the JLARC staff survey.

Part B Services Are Child- Rather Than Family-Focused. Unlike the Part C system, family participation in the Part B system is often limited to parental involvement in service planning, and less frequently entails training on using specific interventions with their child. In fact, only 30 percent of caregivers who responded to the JLARC staff survey indicated that they received the training and support necessary to reinforce at home the services that were provided to their children in preschool. According to local special education directors, schools provide training and other supports to parents as resources allow, and half of schools with preschool classrooms that responded to the JLARC staff survey reported that insufficient resources to train caregivers in ways to reinforce school-based interventions at home was a significant or moderate challenge in meeting the educational needs of students with ASDs. Schools in rural areas were most likely to report insufficient resources to train caregivers as a challenge.

Schools With Preschool Programs Use A Mix of Scientifically Based Practices and Interventions That Are Not Recommended. Eighty-one percent of schools with preschool programs that reported serving students with ASDs indicated they regularly use scientifically based practices such as ABA-based therapies or Learning Experiences: An Alternative Program for Preschoolers and Parents (LEAP), while most (96 percent) reported regularly using promising practices such as Picture Exchange Communication System (PECS) or social stories (see Chapter 2 for categorization of interventions). While these findings are encouraging, the use of scientifically based or promising practices varied by region, according to schools with preschool programs that responded to a JLARC survey. For example, most schools with preschool programs in the Central and Northern Virginia areas reported using scientifically based practices, but a quarter of schools in Southwest Virginia and half in the Tidewater area reported regularly using none. Furthermore, approximately ten percent of schools in the Central Virginia and Charlottesville areas reported using neither scientifically based nor promising practices. Many schools with preschool programs also indicated using practices which current research suggests have little demonstrated effectiveness or are not recommended, which may undermine the effectiveness of services provided to preschool-age children with ASDs. Two-thirds (69 percent) of schools with preschool classrooms reported regularly using interventions with limited support such as Floortime and cognitive scripts, and half (50 percent) reported regularly using practices that are not recommended, such as facilitated communication and holding therapy (Figure 15).

Figure 15: ASD Interventions Used by Schools With Preschool Programs Range From Scientifically Based to Not Recommended



Source: JLARC staff survey of a sample of Virginia public schools, February 2009.

Several factors may limit the extent to which schools use practices that are scientifically based or promising. According to results of the JLARC staff survey of a sample of Virginia schools, the high cost of interventions is a challenge to meeting the educational needs of students with ASDs for 68 percent of schools with preschool classes. In addition, the majority of schools (52 percent) with preschool classes reported that the lack of certification in ASD interventions among school personnel was a challenge. Furthermore, though DOE and its Training and Technical Assistance Center (T/TAC) staff promote the use of research-based practices, DOE has provided mostly informational materials rather than in-depth practical guidance on implementing effective interventions. (See Chapter 7 for more discussion of this issue.)

SERVICE DELIVERY CHALLENGES LIMIT UTILIZATION OF MEDICAID-FUNDED SERVICES FOR YOUNG CHILDREN WITH ASDs

While young children with ASDs can access a variety of services through Virginia's Medicaid program, several service delivery issues undermine the usefulness of its early intervention services. As described in Chapter 3, Virginia children can obtain ASD-related services through waivers as well as the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program, which can serve to supplement or complement interventions provided through the Part C and Part B programs. Many children do not appear to receive services for which they are eligible because of long waiting lists for some waivers, exclusion of certain ASD therapies among waiver services, and limited knowledge about alternative means of securing needed services through EPSDT. In addition, Medicaid providers may not consistently possess the expertise needed to effectively treat children with ASDs. It is important to note that these issues also impact older children and adults with ASDs, as discussed in Chapters 7 and 8.

Some Medicaid-Funded Services Have Limited Utility Because of Program Design, and Others Are Underutilized

Eligible young children with ASDs can access behavioral and developmental therapies primarily through the Mental Retardation (MR) waiver or EPSDT programs, yet few are accessing these services. Few children with ASDs under the age of five received services through the MR waiver, which can serve children under the age of six who are at developmental risk, including children with ASDs. Even though children who are enrolled in Medicaid can receive specialty services such as ASD-specific interventions through EPSDT, Department of Medical Assistance Services (DMAS) staff indicated that they have not received many requests for these services. Finally, a limited number of families have enrolled their child in the Elderly or Disabled with Consumer Direction (EDCD) waiver, even though it is a pathway into EPSDT and ASD-specific interventions such as ABA-based therapies.

Waiting Lists Preclude Many Young Children From Accessing Most Beneficial Waiver. The MR waiver offers a comprehensive array of services that could be beneficial to young children with ASDs, but the waiting list precludes many from accessing it. Nearly 4,400 individuals were waiting for an MR waiver slot at the end of FY 2008, and the waiting list is approximately three years long though some have been on the waiting list for eight or more years. In 2008, only 11 children with ASDs age five or younger were enrolled in the program. In addition to ASD-related behavioral consultation services, young children with ASDs and their families can receive respite, case management, family and caregiver training, day support, and in-home residential supports through the MR waiver program.

Provision of ASD Interventions Is Limited in Waivers. Even though behavioral consultation services are provided through the MR waiver, these services are limited to training caregivers to provide interventions such as ABA-based therapies to their children. As indicated in the discussion of Part C services, parents and other caregivers can be trained to effectively provide interventions to their children, but many may not have the ability to provide at least 20 to 25 hours of intensive services per week, which is recommended in the literature. According to caregivers of children age five or younger who responded to the JLARC staff survey, approximately half (48 percent) are working with their children with ASDs for five or fewer hours per week and only 14 percent are working with their children for more than 15 hours. While direct ABA-based therapies are not covered by waiver programs, children with ASDs can access these services through the Medicaid EPSDT program if a medical need for them exists. However, this requires additional reviews and authorizations, which may be burdensome and delay services.

Families and Providers May Lack Knowledge About Accessing ASD Interventions Through EPSDT. EPSDT is a Medicaid-funded screening program designed to identify physical or mental problems in individuals under age 21. Services that are medically necessary to treat conditions identified during EPSDT screenings must be covered by Medicaid, even if they are generally not covered by the State plan. As a result, children with ASDs who are financially eligible for Medicaid or are enrolled in a waiver program can use EPSDT to access needed ASD-interventions. While these services can be important supplements to those provided by other programs, eligible children with ASDs may not be utilizing ASD interventions because families and providers lack information on how to access these services through EPSDT. In fact, DMAS staff indicated receiving few EPSDT requests for ABA-based or other behavioral therapies. Yet, most parents who spoke during JLARC staff input sessions indicated a need for ABA-based services, which may suggest that the parents of eligible children may be lacking information.

Eligible children with ASDs may not be utilizing ASD interventions because families and providers lack information on how to access these services through EPSDT.

While DMAS staff indicated providing information about EPSDT to families with children enrolled in Medicaid, information about behavioral interventions has not been specifically included. Only physicians, physician assistants, and nurse practitioners can request that a service be reimbursed through EPSDT. As a result, other providers serving young children with ASDs may be unaware of services that can be provided through EPSDT. DMAS staff are currently developing a manual to clarify which behavioral interventions are covered and how services can be accessed to increase provider knowledge.

Few Families Are Enrolling Eligible Children With ASDs in the EDCD Waiver, Thereby Foregoing Access to Other Medicaid-Funded Services. The EDCD waiver offers important services such as respite care to young children with ASDs and their families and acts as a gateway into more intensive behavioral services through EPSDT. Because there is no enrollment limit for the EDCD waiver, any eligible individual can access services immediately. Consequently, some Virginia children with ASDs may be foregoing the opportunity to receive critical early intensive behavioral services. In fact, personnel who conduct eligibility screenings for the EDCD waiver indicated that many children with ASDs could likely qualify for this waiver, but DMAS data indicated only 57 children with ASDs under age five were enrolled in this program in FY 2008 (however, this figure is triple the number enrolled in FY 2007). While the EDCD waiver is designed for the elderly and persons with disabilities of all ages who meet medical and other functional eligibility criteria, young children with ASDs are eligible if they receive occupational, speech, or physical therapy while in school (this meets medical criteria) and need assistance in activities of daily living.

Medicaid Providers Lack Training and Incentives to Become Highly Qualified in Serving Individuals With ASDs

Even if families were better informed about Medicaid coverage for ASD interventions, they may still have difficulty accessing adequate services for their young children with ASDs if providers are not properly trained or widely available. According to caregivers of individuals with ASDs and advocates who spoke during JLARC staff public input sessions, many Medicaid providers are not skilled in serving individuals with ASDs, which can negatively impact the effectiveness of services provided. Moreover, providers may not have adequate guidance or incentives from the Medicaid program to become more qualified in serving this population.

Medicaid Providers Are Not Required to Receive ASD-Specific Training. Medicaid providers, including those providing behavioral interventions, are not required to receive specific training or have experience in serving individuals with ASDs. As a result, providers may lack the knowledge to most effectively provide either behavioral or other services so that they meet the needs of individuals with ASDs. Even providers of behavioral interventions such as ABA-based therapies may not have received training in serving individuals with ASDs. For example, DMAS requires that individuals who provide therapeutic behavioral consultation services be licensed practitioners such as a psychologist or psychiatrist, a certified behavior analyst (certified in ABA), or endorsed as a provider of positive behavioral supports; however, these licenses or certifications do not guarantee that the provider has any experience in or knowledge about serving individuals with ASDs.

Reimbursement Structure May Not Create Incentives for Highly Trained Providers. While Medicaid reimbursement rates for behavioral therapists appear to reflect the average cost of providing ABA-based therapy, they may not be sufficient to attract providers who are highly qualified to serve individuals with ASDs. Reimbursement rates do not increase with greater qualifications or experience, which could serve to encourage Medicaid providers to receive further training or certification. For example, the rate paid to providers of behavioral therapeutic consultation is the same for licensed psychiatrists (doctoral degree), certified behavior analysts (minimum of master's degree) and associate behavior analysts (minimum of bachelor's degree).

OPTIONS TO IMPROVE VIRGINIA'S EARLY INTERVENTION SYSTEM

Virginia could consider several options to improve the delivery of early intervention services to young children with ASDs. In determining whether and which options should be pursued, it may be important to decide upon the specific goals that Virginia wishes to achieve through early intervention services. At the federal level, Part C of IDEA states that Congress found an

> urgent and substantial need…to reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age.

This finding suggests that the intent of IDEA-funded services provided to young children with disabilities is to help them reach a level at which special education services are minimized or no longer needed. If so, then programs for children with ASDs modeled after EIBI or others with similar child outcomes should be the standard by which early intervention programs are designed. Yet, neither Virginia's Part C nor special education programs for preschool-age children appear to be consistently providing young children with ASDs services that are based on effective models of serving young children with ASDs. As a result, these programs may not be fully able to minimize the need for special education and other services among Virginians with ASDs. Given the favorable impact that effective early intervention services have been shown to have on the functional outcomes of individuals with ASDs and public expenditures, several options are offered for incorporating effective practices into Virginia's early intervention programs, addressing issues with Medicaid-funded ASD services, and meeting the early intervention needs of Virginia children outside of existing public programs.

Options Available to Improve Early Intervention Part C Services

Table 16 summarizes key advantages and disadvantages of several options that Virginia could consider implementing to improve the State's Part C system. Some of the items would require additional resources, particularly options to provide more training and expand service options to infants and toddlers with ASDs. However,

Table 16: Advantages and Disadvantages of Options to Enhance Early Intervention Part C Services for Infants and Toddlers With ASDs

Options	Advantages	Disadvantages
Provide Guidance and Training to Providers		
Adopt and update service guidelines for serving infants and toddlers with ASDs	Provide source for consistent and up-to-date information on treatments and their effectiveness Ensure service planning process addresses ASD-related needs Assist program staff and providers to educate families	May result in limited adherence since not policy May undermine focus on individualization of services
Require ASD training for a portion of providers in each local Part C program	Ensure at least some staff/providers in each local program are trained in ASDs Foster efficient/effective service delivery to meet ASD-related needs	Decrease willingness of providers to work with Part C program May exacerbate provider shortage
Enhance Quality Assurance Mechanisms		
Require ASD expert on service planning team	Increase accuracy of assessments Increase appropriateness of service plans Ensure services are meeting goals	Increase logistical difficulties to staff teams for programs with large numbers of children with ASDs
Measure outcomes of infants and toddlers with ASDs	Use data already collected Provide quantifiable information for local programs	May have limited utility if current measures not meaningful for ASDs
Expand Services		
Increase availability of ASD-specific services for infants and toddlers with ASDs	Greater access to intensive ASD interventions Allow flexibility – programs can expand own capabilities or contract with specialty providers	May have limited utility if Part C programs continue to not serve many with ASDs or serve them for short periods Could detract from services provided to infants and toddlers with other disabilities

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

prior to investing additional resources in the Part C program, the State may wish to consider whether (1) it is the best system to provide early intervention services to children with ASDs and (2) opportunities exist to improve the efficiency and effectiveness of existing services because the Part C program does not reach most children with ASDs and usually serves participants for only a few months. Based on results from the JLARC staff survey of caregivers, slightly more than half (56 percent) of children with ASDs under age eight participated in Part C, and most (two-thirds) of those who did were enrolled for less than a year.

Adopt and Update Service Guidelines for Providing Early Intervention Services to Infants and Toddlers With ASDs. The State Part C office could adopt guidelines for serving infants and toddlers with ASDs, resulting in multiple benefits. First, guidelines could provide greater direction to local Part C staff and providers for incorporating into their services the components of effective early intervention programs for young children with ASDs. Second, the guidelines could be a useful tool for program staff and providers to educate families about ASD interventions and what they should expect from the Part C system. Furthermore, guidelines could provide local Part C staff, service providers, and families with consistent and current information as to the effectiveness of particular treatments. In essence, adopting guidelines could be an important step toward bringing staff, providers, and families onto the "same page," which State Part C staff indicated is needed.

Service guidelines for serving young children with ASDs have been developed in other states, including New Jersey, New York, South Carolina, and Connecticut. In addition to drafting guidelines for the Part C system, which serves children two and under, Virginia could follow the example of other states (New Mexico and Maryland) and develop guidelines for children with ASDs during the entire early intervention period, which is often described as ranging from birth to age five. Developing guidelines that cover a broader age range could help foster consistency in treatment methods across programs.

Development costs would likely be minimal because a special committee of the Virginia Association of Community Services Boards (VACSB) is already working on service guidelines for the Part C system. Resources would, however, be needed to train local Part C staff and service providers on how to utilize the guidelines. In addition, staff resources would be required to ensure that the guidelines remain up-to-date with the ASD literature.

Require ASD Training for a Portion of Early Intervention Providers. Another option that Virginia could pursue to improve the delivery of services to infants and toddlers with ASDs is to require ASD-specific training for a minimum proportion of local Part C program staff and service providers in each of the 40 service areas. Requiring some providers to receive training could serve to increase the ability of local programs to assess the needs of infants and toddlers with ASDs, design appropriate service plans to address their needs, and ensure services are appropriate and provided effectively so that infants and toddlers with ASDs can achieve desired outcomes. While the State Part C office could require all Part C service providers to receive ASD training, this approach may not be necessary because only four percent of the infants and toddlers served through the Part C system have an ASD diagnosis or are suspected of having an ASD.

The Virginia Autism Council (VAC) and the Integrated Training Collaborative (which develops and provides training for early intervention providers) have already collaborated to develop ASD-specific training strategies for Part C providers, which should be available in May 2009. In addition, DOE has developed a professional development tracker that identifies the various areas in which service providers should be knowledgeable to effectively serve individuals with ASDs. This tracker could be used as a tool for Part C providers to identify areas where training is needed. A more detailed discussion on VAC training, the skills competencies, and the tracker is provided in Chapter 7.

Require ASD Expert to Be Part of Service Planning Team. Because individuals with ASDs have such unique needs and often require unique teaching styles, the State Part C office could consider requiring an "ASD expert" to be part of the Individualized Family Service Plan (IFSP) team for infants and toddlers with or suspected of having an ASD diagnosis. Implementing this option would serve to increase the ability of local programs to assess the needs of infants and toddlers with ASDs, design appropriate service plans to address their needs, ensure services are provided effectively, and assist the family in understanding ASDs and the interventions that can be provided. In order to effectively implement this option, the State Part C staff could provide guidance on the qualifications needed to be considered an ASD expert. For example, New Jersey's Part C system requires that the assessment team for children with ASDs or suspected ASDs include at least one member who has had two or more years of professional experience working directly with young children (birth to five) with ASDs and their families. The ASD expert could be a local Part C staff person or a service provider contracted by the Part C system.

Measure Outcomes Specifically for Infants and Toddlers With ASDs. The Part C system could use already collected data to track the outcomes of participants with ASDs or suspected ASDs. Analyzing outcomes would inform the State Part C office and local programs on whether services provided to infants and toddlers with ASDs are having the desired impact overall, services need to be adjusted to achieve the desired impact, and local programs need additional assistance to improve service delivery. While three measures of progress are reported for all children served through Part C, the State Part C office could analyze and report these outcomes by disability. The State office also conducts a survey of families whose children receive Part C services, and a new field capturing the type of disability could be added to the survey so that the results could be analyzed specifically for infants and toddlers with ASDs.

Provide Additional Resources to Expand Service Options for Infants and Toddlers With ASDs. The State could consider providing additional resources to the Part C program to expand its capabilities to provide more intensive services and use interventions which have been found effective for young children with ASDs (such as ABA-based therapies or PECS). Even though the General Assembly substantially increased State general fund dollars for the Part C system in FY 2007 (from $3.1 million to $7.2 million), the annual amount spent per child is still much lower ($4,148) than the estimated cost of intensive treatment for ASDs ($23,00 to $60,000).

Several states have developed systems in which infants and toddlers with ASDs can access specialized services. In Connecticut, for example, families of children with ASDs have the option of receiving services from a Part C autism program that serves the region in which they live. While these programs specialize in serving young children with ASDs, they must also provide all other early intervention services that the child and family needs. In Massachusetts and Rhode Island, infants and toddlers with ASDs can receive specialty services from approved providers in addition to other early intervention services provided by their local Part C program, to ensure that services meet their specific needs. The ability to access specialized services, however, may result in higher annual per child costs. For example, the annual amount spent per child in Connecticut in FY 2008 ($8,451) is twice what Virginia spent during the prior fiscal year. Both amounts, however, represent the average cost of serving any infant or toddler rather than strictly infants or toddlers with ASDs.

Another option that Virginia could consider would be for the Part C system to partner with school divisions to provide a seamless system of care to children with ASDs. This option would have the benefit of leveraging the strengths of both the Part C and Part B systems as well as addressing issues in both systems concurrently. For example, school districts in the state of Washington must partner with local Part C programs to provide early intervention services to children birth through age two. Schools fund services for infants and toddlers with state special education funding, and those served are included in their funding formula. Schools in Washington must also comply with all Part C regulations in serving this population. For example, infants and toddlers served by the schools still have an IFSP rather than the IEP that is used for all other special education students age three to 21.

Options Available to Improve School Part B Services for Young Children with ASDs

As shown in Table 17, Virginia could consider several options for improving the delivery of School Part B services to preschool-age children with ASDs. The options discussed in this section focus on two components that are particularly important for young children with ASDs according to the literature: family support and training,

Table 17: Advantages and Disadvantages of Options to Enhance School Part B Services for Young Children With ASDs

Options	Advantages	Disadvantages
Increase Training and Support for Families		
Increase family training opportunities	Greater ability of parents to engage child in meaningful activity Increases child's ability to generalize and maintain skills	Requires staff training in parent education strategies Dependent on parents' ability and willingness to participate
Increase Structure and Intensity of Programs		
Increase availability of in-home services	Increases child's ability to generalize and maintain skills Increases amount of active participation	Requires coordination with family or other caregiver schedules
Increase resources to provide lower child-to-staff ratios	Greater ability to provide individualized instruction Could allow for greater integration with typically developing peers Greater ability to collect data, monitor child progress	May result in greater use of paraprofessionals who lack ASD-specific training
Increase availability of full-day, year-round preschool	Increases time to provide intensive instruction Reduces regression during holidays	No benefit for preschool-age students with ASDs served in other settings

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

and the intensity and structure of treatment programs. The State could also pursue several options that would benefit all students with ASDs (these options are discussed in Chapter 7).

Provide Greater Support and Training for Families. Providing greater training and support to families is one option the State could consider to improve services for preschool-age children. Virginia could model a parent training program after one that was piloted and is presently being expanded statewide in Oregon. Oregon's Regional Program Autism Training Sites (RPATS) provide training to ASD specialists and teachers so that they can implement training programs for parents of children within their school system. During evening group workshop sessions that meet for several weeks, parents are taught ways to interact with their child to improve parent/child communication and social interaction. Virginia could develop a similar model using the regional Training and Technical Assistance Centers (T/TAC), which function similarly to Oregon's RPATS. While T/TACs have a broader focus, most employ staff with experience and training to work with individuals with ASDs. In addition, many school divisions have ASD specialists or teams that could be utilized to train parents.

Increase Structure and Intensity of Preschool Services. Virginia could consider providing greater opportunities for young children with ASDs to receive the structured and intensive services that are recommended in the literature through preschool programs. Structure and intensity could be improved by providing additional resources for:

- staff who provide in-home services;
- low child-to-staff ratios (1:1 or 2:1), at least initially; and
- full-day programs that continue during the summer.

Technically, schools must provide services that meet these criteria if it is written in a student's Individualized Education Program (IEP); however, resource constraints may limit the ability of some school divisions to provide some of these services directly and to the extent that would most benefit the student. For example, staff from several school divisions indicated that they would like to directly provide summer programming for their preschool-age children with ASDs. While private programs and in-home services are an option for summer programming, switching children with ASDs from one program to another may negatively impact the progress they can make, particularly since they often do not respond well to changes in routine. It is also important to note that some of these options may require adjusting the SOQ formula which prescribes maximum staffing ratios. Currently, SOQ staffing ratios for preschool classrooms containing children with ASDs are staffed at 6:1 (child:staff) or 8:2 (including a paraprofessional), but these ratios neither account for the age of the student nor the severity of ASD symptoms. Virginia could consider revising the SOQ formula to include a tiered staffing ratio for serving this population based on severity of ASD symptoms or age.

At least one school district in Virginia already provides full-day preschool classrooms that have low child-to-staff ratios and continue through most of the summer, as described in the following case study:

> ***Case Study***
>
> *Fairfax County Public Schools offers full-day classrooms with a 2:1 child-to-staff ratio to 166 preschool-age children with ASDs. The goal of the program is to prepare students with ASDs to function as independently as possible in a variety of settings by providing an educational environment that enhances academic, communication, social/emotional, and adaptive skill development. The principles of ABA and Verbal Behavior Analysis (VB) are used as the fundamental approach to teaching students and addressing problem behaviors. Other features of this program include training and technical support from ABA resource teachers, consultation with ABA and VB experts to guide the program, and monthly workshops for parents. Services are provided dur-*

> *ing the summer for six weeks, and 38 classrooms are in operation at 23 schools. According to a 2006 report, the cost of the preschool program (and a similar elementary program) was approximately $7.7 million in FY 2006. In addition, the report noted that students have met stated objectives of demonstrating improvements in behavior, communication skills, and motor skills between the fall of 2005 and spring of 2006, as measured by formal assessments.*

Virginia could also consider adopting a tiered approach to providing preschool programs for children with ASDs, similar to the approach used in Howard County, Maryland, where children with developmental disabilities can be placed in one of three classrooms based on their level of delay in behavior, cognition, functional communication, engagement, and social interaction. The structure and intensity of each classroom is illustrated in Table 18. Of note, each classroom includes typically developing peers, which is an important component for special education programs according to the child development literature. While these classrooms are available to all children with developmental disabilities, some are designed to specifically serve children with ASDs; those classrooms were developed in consultation with staff from the Walden School at Emory University (considered by the literature to be a model program for serving students with ASDs). Staff indicated that this program has resulted in fewer out-of-school placements and due process proceedings, both of which are costly.

It is important to note that providing structure and intensity alone will likely not maximize child outcomes. Consequently, efforts to improve preschool programs for students with ASDs could also ensure that interventions are effective through the use of research-based practices, qualified staff to implement practices, appropriate curriculum to address the needs of students with ASDs, and outcomes assessments. Strategies to achieve these goals are discussed in Chapter 7.

Table 18: Schools in Howard County, Maryland, Provide Preschool Classes Based on Tiered Structure

	Classroom, by Level of Child's Delay		
Component	**Mild to Moderate**	**Moderate to Severe**	**Severe**
Intensity	10-12.5 hours per week	Average of 28.5 hours per week	Average of 28.5 hours per week
Classroom setting	With typically developing peers	With typically developing peers	With typically developing peers in morning
In-home services	Up to 1 hour per week	As needed	As needed
Staff:Child ratio[a]	2:8:4	4:6:4-6	5:5:5
Other		Family training at school	Family training at school

[a] Staff:children with ASDs:typically developing children.

Source: Howard County Public Schools, Overview of Services and Programs.

Options Available to Improve Medicaid-Funded Services Available to Young Children With ASDs

Medicaid-funded services that are available for young children are not specifically designed to address the needs of individuals with ASDs. In addition, families are not fully aware of services for which their children may be eligible, particularly services through the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program. Virginia could consider options to improve the delivery of Medicaid-funded services for young children with ASDs that range from providing better information about services currently available to developing a separate waiver for individuals with ASDs (Table 19). It should be noted that implementing these options could benefit Medicaid recipients with ASDs of all ages, not only young children. However, improving Medicaid programs will only benefit some children with ASDs, because (1) not all children are financially eligible for Medicaid and (2) waiver services will only benefit those who meet the criteria for institutional care.

Knowledge of Families and Providers Could Be Improved. Virginia could consider several options to improve knowledge of Medicaid-funded services. First, an information packet for case managers, families, and providers could be developed to describe the Medicaid-funded services available to young children with ASDs. The packet could also be made available to service providers such as developmental specialists and local Part C programs for their use in helping educate families about the options available to their children, including ASD-specific services and how they can be obtained through Medicaid. In addition, this resource could stress the importance of seeking waiver services for eligible children with ASDs as early as possible given long waiting lists.

Because of the substantial and immediate benefits that Virginia families could derive from enrolling in existing Medicaid programs that are underutilized, the Department of Medical Assistance Services (DMAS) should undertake an educational initiative about available services. Specifically, information provided by DMAS could more clearly explain to providers and families that children with ASDs who are enrolled in Medicaid can access ASD interventions such as ABA-based therapies through EPSDT if a medical need exists for these services. In addition, the information could explain that children who are otherwise not financially eligible for Medicaid but meet the Elderly and Disabled with Consumer Direction (EDCD) waiver requirements can access specialty services through EPSDT as well as other Medicaid-funded services. Because the EDCD waiver does not have a cap on the number of slots, any child with an ASD who meets the criteria could enroll. While clarifying these methods of obtaining Medicaid-funded services through the EDCD waiver or EPSDT could have a significant

Table 19: Advantages and Disadvantages of Options to Enhance Medicaid-Funded Services Available to Young Children With ASDs

Options	Advantages	Disadvantages
Increase Family and Provider Knowledge		
Develop information packet about ASD services and available Medicaid resources	Increase knowledge of families, case managers, providers	None
Adopt service guidelines for serving individuals with ASDs	Provide source for consistent and up-to-date information on treatments and their effectiveness Ensure service planning process addresses ASD-related needs	May result in limited adherence since not policy
Require providers to complete ASD training	Increase provider knowledge of ASDs Increase provider ability to provide appropriate and meaningful services	Decrease provider willingness to serve this population
Develop ASD Provider Standards and Rates		
Create ASD provider category and standards	Increase visibility of ASD services Assist families in choosing qualified providers	No benefit if providers unwilling or not qualified to provide ASD services
Tier ASD provider rates	Increase in providers specializing in ASDs Allow rates to differ based on provider qualification, intensity of service	None
Adjust Waiver Services		
Allow direct provision of ASD therapies in current waivers	More appropriately meet intensive therapy needs of clients with ASDs Increase waiver providers who specialize in ASD treatments Streamline process of obtaining ASD interventions Allows for case management of ASD interventions	Requires federal approval No benefit for those on waiting list or who do not meet eligibility
Create New Waiver		
Create waiver specifically for individuals with ASDs	Service package designed specifically for ASDs More appropriately meet intensive therapy needs of clients with ASDs Increase waiver providers who specialize in ASD treatments Streamline process of obtaining ASD interventions Allows for case management of ASD interventions Eliminate competition with other disability populations for waiver slot	Requires federal approval No benefit for those on waiting list or who do not meet eligibility Increases competition among waivers for limited resources Inconsistent with recent efforts to develop cross-disability programs

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

fiscal impact, the extent of the impact is unknown because it is unclear how many children with ASDs meet both the medical and functional criteria for the EDCD waiver, or have a medical need for ASD-specific services.

Recommendation (4). The Department of Medical Assistance Services should develop and implement a plan for educating Virginians with autism spectrum disorders (ASDs) and their families; Medicaid case managers; providers; and personnel from relevant programs including School Part B, Early Intervention Part C, and Comprehensive Services Act about the availability of Medicaid waivers and programs through which needed services can be obtained. In particular, outreach efforts should convey that individuals with ASDs may be eligible for the Elderly or Disabled with Consumer Direction waiver, and that Medicaid and waiver recipients under age 21 can receive a comprehensive array of medically necessary services through the Early and Periodic Screening, Diagnosis, and Treatment program. The department should present a detailed plan outlining its proposed outreach efforts to the Joint Commission on Health Care no later than November 30, 2009.

DMAS could also consider adopting guidelines to ensure that providers offer treatment that best meets the needs of individuals with ASDs and are based on up-to-date research. The Part C guidelines that are currently being developed could be adopted by DMAS with some modifications. Guidelines could also help case managers and other providers to develop appropriate service plans for young children with ASDs.

Medicaid providers who serve individuals with ASDs could also be required to receive ASD training. The training that has been developed for Part C staff as well as the Virginia Autism Council's (VAC) skills competencies could be used for this purpose. DMAS could partner with VAC staff to determine whether current training materials are relevant for their providers and then develop more appropriate content if needed.

Category of ASD Providers Could Be Developed, and Reimbursement Rates Tiered by Qualification. DMAS could consider developing a category of providers that specialize in serving individuals with ASDs. This option could serve to improve provider quality and assist families in choosing the most appropriate providers for their children with ASDs. Specifically, DMAS could develop standards or qualifications for individuals who provide ASD interventions, and also tier the reimbursement rates based on the intensity of services and provider qualifications. This structure may not result in a higher average cost because not all children require the highest available skill level, but it could encourage some providers to become more highly qualified to serve children who need a high level of care. Some Medicaid rates are already tiered in this way. For example, reimbursement rates for day support services provided through the MR and DD waivers differ by high and regular intensity, and rates for skilled nursing services differ depending on whether services are provided by a licensed practical nurse or registered nurse. Several states have developed specific Medicaid categories for ASD providers and tiered the reimbursement rates based on provider qualifications and level of service provided; Table 20 illustrates an example from South Carolina.

Current Waivers Could Include Direct Provision of ABA-Based and Other ASD Therapies. Given the importance of providing intensive early intervention services, Virginia may wish to include in its waivers the direct provision of ASD interventions such as ABA-based and other developmental therapies. While waiver programs include consultation services to parents, this model relies heavily on the ability and willingness of parents to engage their children in intensive interventions. This service would be especially important for the MR waiver, which is the only comprehensive waiver for young children at developmental risk due to ASDs. Although long waiting lists may currently preclude young children from benefiting from MR waiver services, the General Assembly has directed DMAS to begin taking action to eliminate waiver waiting lists. Though the pace at which the waiting list could be eliminated

Table 20: South Carolina's Medicaid Program Has Developed ASD Provider Categories With Tiered Reimbursement Rates

Provider Type	Summary of Qualifications[a]	Level of Services	Hourly Rate
EIBI Consultant	Master's degree and certification in behavior analysis and one year of experience in field Bachelor's degree and certification in behavior analysis and two years' experience in field	Oversees development and implementation of service plan Educates caregivers and other service providers	$60
Lead Therapist	Bachelor's degree in behavior analysis, education, or psychology, and at least 500 hours of supervised experience in field	Assures treatment provided according to service plan Reviews all recorded data Provides guidance to other therapists	$30
Line Therapist	High school diploma At least 12 hours of training in ABA-based therapies Annual in-service training on ABA-based therapies	Implements treatment plan Records data	$14

Note: EIBI, early intensive behavioral interventions.

Source: South Carolina Department of Developmental Disabilities and Special Needs documents.

is unknown, seeking General Assembly and federal approval to implement these therapies in the MR waiver will likely be a lengthy process.

While young children with ASDs can access direct ABA-based and other developmental therapies through EPSDT, including these services in the MR waiver would allow for a more seamless system. For example, MR waiver case managers would determine the need for these therapies and families would not have to seek additional approval through EPSDT, which requires a formal request by a physician. Several states including Alaska, Illinois, New York, and Wisconsin include the direct provision of behavior therapies within their developmental disabilities waiver (Table 21). For example, Wisconsin includes intensive in-home treatment in its Children's Long-Term Support Waiver, which serves children with developmental disabilities. In order to be eligible for this service, children must be medically diagnosed with an ASD, between the ages of three and eight when eligibility is determined, and assessed as able to benefit from an intensive level of service. While the service model is ABA-based, Wisconsin staff indicated other services can be provided as long as they are research-based. Children who receive intensive in-home services engage in approximately 25 to 30 hours each week of one-to-one intervention for a maximum of three years. After three years of intensive services (or sooner if intensive services are no longer required) children can transfer to the long-term support waiver and continue to receive supportive services until they reach age 22.

New ASD-Specific Waiver Could Be Created. Rather than incorporating the direct provision of behavioral therapies into existing

Table 21: Developmental Disability Waivers in Some States Include Intensive Services for Individuals With ASDs

State	Age Group	Selected Services Included in Waiver	Cost Per Person[a]
Alaska	All ages	Care coordination; day habilitation; intensive active treatment[b]; residential habilitation; respite care; supported employment	$70,905
Illinois	3 to 21	Adaptive equipment; assistive technology; behavioral interventions[b]; caregiver training; personal support; service facilitation	$13,415
New York	Birth to 20	Family caregiver supports and services; day habilitation; intensive in-home supports and services[b]; respite care; skill building; vocational and prevocational services	$29,219
Wisconsin	Birth to 21	Adaptive and communication aids; daily living skills; day habilitation; in-home autism treatment[b]; respite care; service coordination	$15,767[c]

[a] Average projected cost for 2009 included in the waiver application to the federal Centers for Medicare and Medicaid Services.
[b] Intensive interventions addressing ASD-related needs.
[c] Average cost based on report by Wisconsin Legislative Fiscal Bureau, 2009.

Source: JLARC staff review of state applications for home and community based waivers specifically serving individuals with ASDs.

waivers, Virginia could consider creating a new waiver that specifically serves individuals with ASDs. Based on a review of ASD waivers in other states, Virginia could design such a waiver to reach individuals who require more intensive services to meet their ASD-related needs, and could limit enrollment to a specified length of time or to a particular age group. A group of Virginia stakeholders is currently being assembled by DMAS to explore this possibility and should complete its work by the fall of 2009.

Indiana and Maryland have provided ASD waivers for some time. Since 1990, Indiana has provided an ASD waiver to individuals who would require an institutional level of care. While there is no specific age criterion for the ASD waiver, children between ages two and seven are eligible to receive ABA-based therapies. In addition, children and other individuals with ASDs can receive behavior support services, respite care, and training for family members or other caregivers. Since 2001, Maryland has provided a waiver for children ages one through 21 with ASDs who are served through the Part C or special education system and meet an institutional level of care. Waiver recipients have access to intensive one-on-one support services for up to 30 hours per week and can receive structured programming that focuses heavily on expressive therapies and therapeutic recreational activities for up to four hours after school. The Maryland Department of Education administers the daily operations of the waiver, and service coordination for each participant is provided by local school systems. Table 22 illustrates the age groups served, services included, and average costs of autism waiver programs in several states.

Table 22: Autism Waiver Programs in Other States Vary in Age Groups Served, Services Included, and Average Costs

State	Age Group	Selected Services Included in Waiver	Cost Per Person[a]
Indiana	All ages	Adult day services; behavioral support[b]; family and caregiver training; occupational, physical, and speech therapy; recreational therapy; residential habilitation; respite care	$34,759
Kansas	Birth to 5	Intensive individual supports[b]; respite care; Autism Specialist (Consultative Services); parent support and training	$33,565
Maryland	1 to 21	Adult life planning; environmental accessibility adaptations; family training; intensive individual support services[b]; residential habilitation; respite care; therapeutic integration	$33,669
Massachusetts	Birth to 8	Adaptive aids/assistive technology; family training; habilitation and expanded habilitation/education[b]; respite care	$25,811
Montana	1 to 4	Adaptive equipment; autism training[b]; case management; occupational, physical, and speech therapy; respite care	$44,269
South Carolina	3 to 10	Service coordination and early intensive behavioral intervention[b]	$33,900

[a] Average projected cost for 2009 included in the waiver application to the federal Centers for Medicare and Medicaid Services.
[b] Intensive interventions addressing ASD-related needs.

Source: JLARC staff review of state applications for home and community based waivers specifically serving individuals with ASDs.

Additional Options to Improve Virginia's Early Intervention System

Rather than providing more intensive or specialized services through existing programs, Virginia could consider supplementing the services received through the Part C, special education, and Medicaid programs (Table 23). For example, children with ASDs could access supplemental services through a regional office, as well as attend a private school of their parents' choice. These options are not mutually exclusive, and could also be implemented in combination with improvements made to existing programs.

Deliver ASD Services Through Regional Offices. Rather than modifying the structure of existing programs, Virginia could begin delivering early intervention services to young children with ASDs through regional offices. Similar options as those described in Chapters 4 and 5 could be used to provide these services. Child development clinics (CDCs) could provide direct services to young children with ASDs if additional resources were provided to add new sites, hire personnel with expertise in ASDs, and increase staffing in order to provide in-home or other community-based services so that they also meet Part C criteria for serving infants and toddlers in natural environments. Virginia could also consider expanding the capabilities of the 40 community services boards (CSBs) to provide direct services to young children with ASDs. Many of the local Part C programs are already housed in CSBs, and the CSBs have better statewide coverage than CDCs. In addition, Part C and CSB staff could work together, which would aid in the continuity of services and simplify the service delivery system.

Table 23: Advantages and Disadvantages of Additional Options to Improve Virginia's Early Intervention System

Options	Advantages	Disadvantages
Deliver ASD Services Through Regional Offices		
Community Services Boards	Use of existing infrastructure House most Part C offices Distributed regionally (40 locations)	Has focused on intellectual rather than other developmental disabilities
Child Development Clinics	Use of existing infrastructure Have clinical expertise	Limited to nine locations statewide
University-Based Centers	Have clinical expertise	No existing infrastructure
Offer Educational Alternatives		
Autism Tuition Grant Program	Increases parent/caregiver choices Increases access to more specialized services Creates competition for public schools	May not cover all costs leading to inequity Does not hold private schools to IDEA or No Child Left Behind standards

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

Lastly, Virginia could consider utilizing university-based regional centers. As with the CDCs, these university-based centers would need the flexibility to provide services in the home or other community settings to provide Part C funded services.

Implement an Autism Tuition Grant Program. Finally, the Virginia General Assembly could reconsider legislation to implement the Virginia Autism Tuition Grant Program. Legislation introduced during the 2009 General Assembly session would have created a grant program allowing parents to use vouchers to send eligible children with ASDs to a nonsectarian private school, another public school within their district, or a public school in an adjacent division.

In recent years, multiple states have implemented (Arizona, Florida, Ohio, and Utah) or considered (Kentucky, Kansas, Mississippi, South Carolina, and Texas) similar voucher programs for special education students. Ohio created a program in 2004 specifically for students with ASDs. One difference between Ohio's grant program and the program parameters considered by Virginia lawmakers is that parents in Ohio can choose private providers that are not school-based.

An analysis of Ohio's program showed that while parents were satisfied with the services their children received, there were several issues that the Virginia General Assembly may wish to explore if it reconsiders a grant program in future legislative sessions:

- Families living in more affluent communities tend to use the program more than families from poorer communities.
- Oversight and accountability are lacking as parents are largely responsible for holding private schools and providers accountable. The state provides minimal oversight of services.
- Parents surrender the right to a free and appropriate education which is guaranteed by IDEA.
- Private schools and providers are concentrated in urban areas outside of reasonable driving distance for many families.
- Few private schools and providers accept children with more severe disabilities.

The Ohio study recommended that public resources be redirected toward strengthening services for all children with ASDs through collaboration between schools, other public agencies, regional service centers, higher education centers, and private providers.

Summary of Options to Enhance the Early Intervention System for Children With ASDs

In addition to having different policy merits, options described in this chapter vary in terms of the financial and human resources required, the extent to which they address the issues discussed in this chapter, and the time needed for implementation. Figure 16 summarizes these implementation considerations and reflects the best judgment of JLARC staff based on discussions with experts and knowledge gained during this review. To facilitate the State's decision whether and how to enhance the early intervention system for children with autism spectrum disorders, the State departments of Behavioral Health and Developmental Services, Education, and Medical Assistance Services should collaborate with relevant stakeholders to weigh policy and implementation considerations, and identify which options are most suitable to reshape the programs administered by their agencies.

Recommendation (5). The Department of Behavioral Health and Developmental Services should collaborate with relevant stakeholders to (1) evaluate the options for enhancing the early intervention system for children with autism spectrum disorders by improving the Early Intervention Part C program and developing services through regional offices; and (2) identify no later than March 31, 2010, which, if any, options are most beneficial to pursue.

Recommendation (6). The Department of Education should collaborate with relevant stakeholders to (1) evaluate the options for enhancing the early intervention system for children with autism spectrum disorders by improving the Part B special education services available to preschool-age children and offering educational alternatives through a scholarship program; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

Recommendation (7). The Department of Medical Assistance Services should collaborate with relevant stakeholders to (1) evaluate the options for enhancing the early intervention system by improving the Medicaid programs serving young children with autism spectrum disorders; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

Figure 16: Implementation Considerations for Options to Improve Early Intervention Services for Young Children with ASDs

Major Goal	Resources Needed	Extent to Which Addresses Major Goal[a]	Time Needed to Implement
Improving Early Intervention Part C Services for Infants and Toddlers With ASDs			
Provide Guidance and Training to Providers			
Adopt and update service guidelines	↓	★	🕓
Require ASD training		★★	🕓🕓
Enhance Quality Assurance Mechanisms			
Require ASD expert on service planning team		★★	🕓🕓
Measure outcomes of infants and toddlers with ASDs		★★	🕓🕓
Expand Service Options			
Increase availability of ASD-specific services		★★★	🕓🕓🕓
Improving School Part B Services for Preschool Aged Children With ASDs			
Increase Training and Support for Families			
Increase family training opportunities	↓	★	🕓🕓
Increase Structure and Intensity of Programs			
Increase availability of in-home services		★★	🕓🕓🕓
Increase resources to provide lower child-to-staff ratios		★★	🕓🕓🕓
Increase availability of full-day, year-round preschool		★★	🕓🕓🕓
Improving Medicaid Programs for Young Children with ASDs			
Increase Family and Provider Knowledge			
Develop information packet of ASD services	↓	★★	🕓🕓
Adopt guidelines for serving individuals with ASDs		★	🕓🕓
Require providers to complete ASD training		★★	🕓🕓🕓
Develop ASD Provider Standards and Rates			
Create ASD provider category and standards		★★	🕓🕓
Tier ASD provider rates		★★	🕓🕓🕓
Adjust Waiver Services			
Allow direct provision of ASD therapies in current waivers		★★★	🕓🕓🕓
Create New Waiver			
Create waiver specifically for individuals with ASDs		★★★	🕓🕓🕓
Developing New Programs to Provide Early Intervention Services			
Deliver ASD Services Through Regional Offices			
Community Services Boards	↓	★★	🕓🕓🕓
Child Development Clinics		★★	🕓🕓🕓
University-based clinics		★★	🕓🕓🕓
Offer Educational Alternatives			
Autism Tuition Grant Program		★	🕓🕓

Least
↓
Most

★ Somewhat
★★ Substantially
★★★ Greatly

🕓 < 6 Months
🕓🕓 6-18 Months
🕓🕓🕓 > 18 Months

[a] Ratings reflect the extent to which each option addresses the major goal described in the gray-shaded row.

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

Chapter 7

Improving the Delivery of Services to School-Age Virginians With Autism Spectrum Disorders

In Summary

While the federal government intends for schools' special education programs to improve the ability of students with disabilities to learn and interact with their nondisabled peers, as well as ultimately prepare them for future independent living, Virginia schools appear unable to uniformly identify and implement the services necessary to further these goals for students with ASDs. This appears due to a lack of practical guidance on ASD-specific instruction and professional development programs that lack the capacity to provide the ASD-specific training and technical assistance required by school staff. Many Virginia schools also appear to lack the resources and expertise to develop and implement effective service plans for transitioning students to adult life. Despite having limited resources dedicated to ASD-specific initiatives, the Department of Education has undertaken several efforts to improve schools' capacity to serve these students, and options exist for the agency and the General Assembly to expand upon current efforts. In particular, there are options to expand schools' access to ASD experts, identify and prioritize teachers' training needs, enhance schools' capacity to measure and use data on student progress, and broaden opportunities for these students to prepare for adult life.

The federal Individuals with Disabilities Education Act (IDEA) requires that public schools provide all students who require special education services, including those with autism spectrum disorders (ASDs), a free and appropriate public education to meet their unique needs and prepare them for further education, employment, and independent living. However, it appears that Virginia students with ASDs are not uniformly receiving the types or intensity of services from schools that are needed for them to achieve some measure of independence once out of school.

Virginia's public schools are the primary providers of services for most children with ASDs, and have experienced a steady annual increase in the numbers of students with ASDs ranging in age from two to 21 during the last decade. This has required an escalation of school resources and expertise, but schools have yet to build sufficient capacity to fully meet the needs of these students and their families.

Schools' difficulties in serving students with ASDs may be due, in part, to State-level resource constraints that have inhibited the Department of Education's ability to provide practical and in-depth guidance on the most effective strategies for educating these students and preparing them for independent living. In addition, insufficient oversight and training programs across the State have resulted in a lack of uniform school policies and practices, varied levels of awareness about ASDs, and limited expertise in applying the interventions that are considered most effective for students with ASDs.

Chapter Research Methods

JLARC staff interviewed a variety of stakeholders, including staff from the Virginia Department of Education and its Training and Technical Assistance Centers (T/TACs), members of the Virginia Autism Council (VAC), and special education staff within eight school divisions. In addition, staff conducted surveys of a sample of 26 percent (560) of public schools, as well as individuals with ASDs and their caregivers. Staff also conducted an extensive review of the research literature and practices used in other states. Additional details on study research methods can be found in Appendix B.

VIRGINIA STUDENTS WITH ASDs ARE ENTITLED TO SERVICES THAT PREPARE THEM FOR INDEPENDENCE

Schools' primary responsibility to students with ASDs—and all types of disabilities—is to provide a free and appropriate public education, but there appears to be a lack of clarity around the operational meaning of this term. According to IDEA, an appropriate education includes "special education and related services designed to meet [students'] unique needs and prepare them for *further education, employment, and independent living*." Absent a more specific performance measure, this is the standard to which the State, localities, and families hold schools.

Two issues have historically obscured the clarity of the meaning of the appropriate education standard. First, neither the federal government nor the Virginia Department of Education (DOE) has provided a clear definition of the term "appropriate education," and second, the nature of "appropriate" is likely to vary based on the individual needs and abilities of each student. The lack of a precise standard against which to hold school-based services accountable has resulted in inconsistent perceptions among families and school personnel about the scope of schools' responsibilities for educating students with disabilities, including ASDs.

Individualized Education Program

Schools must develop an Individualized Education Program (IEP) for each student who requires special education services. The IEP specifies the educational needs of the child and what special education and related services are necessary to meet those needs. The IEP is developed by a multidisciplinary team of school personnel with input from the student's parents, as well as the student.

Although school staff interviewed across the State did not express confusion about the meaning of "appropriate," their interpretation of the standard varied greatly between and within school divisions. In a staff survey of a sample of schools, one special education director defined appropriate education as providing special education students with a "level playing field" for learning as compared to non-disabled students, while another stated that students are receiving appropriate education as long as they are making progress toward goals and objectives. DOE staff have stated that school personnel are offering an appropriate education as long as they are providing the services included in a student's Individualized Education Program (IEP). Further, while schools generally take the position that an appropriate education entails giving special education students learning opportunities that are equal to those afforded to their non-disabled peers, parents are more likely to expect schools to provide their children with the best possible education.

Interpreting the meaning of "appropriate" has largely been left to the U.S. justice system, and the numerous court decisions on this issue have resulted in a variety of definitions. The most often cited legal decision is *Board of Education v. Rowley* (1982) in which the U.S. Supreme Court held that "students with disabilities are entitled to an individualized educational program with services reasonably calculated to confer educational benefits." This has been commonly interpreted to mean that schools are not expected to provide students with disabilities the best of all possible educations. It should be noted that this decision was made prior to the latest reauthorization of IDEA, which now emphasizes independent living as the ultimate purpose of appropriate education. Consequently, the *Rowley* decision that is most commonly used to explain the appropriate education standard did not address the obligation of schools to prepare students for independent living as set forth in the reauthorization. In fact, a 2006 U.S. District court case in the Ninth Circuit, K.L. v. Mercer Island School District, found that "providing a meaningful educational benefit under the IDEA requires programs and results which reflect the Act's emphasis on preparation for self-sufficiency." However, no Fourth Circuit court decision has addressed the issue.

Recommendation (8). The Virginia Department of Education should collaborate with the Office of the Attorney General to develop operational guidelines for schools on the provision of a free and appropriate public education for students with disabilities, as determined by federal and state legal decisions.

MOST SCHOOLS ARE CURRENTLY UNABLE TO MEET THE NEEDS OF ALL STUDENTS WITH ASDs IN A CONSISTENT MANNER

While Virginia schools report generally being able to provide an appropriate education to students with ASDs, it appears that most struggle to fully meet their multifaceted needs. Schools appear to successfully meet process requirements outlined in IDEA such as providing adequate opportunities for being educated alongside non-disabled peers ("inclusion"), offering services in an appropriate setting, and including parents in the IEP process. However, many schools appear unable to shape outcomes by addressing the core deficits of ASDs, providing instruction that allows students to generalize skills to settings other than schools, and ultimately reducing the need for special education services.

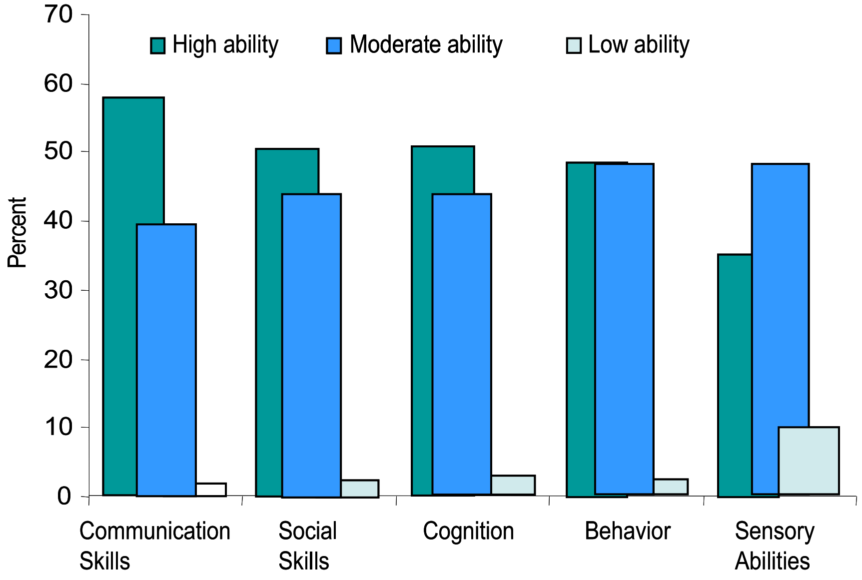
Virginia Schools Appear to Adequately Provide Inclusion Opportunities and Involve Parents

Schools appear to educate children with ASDs in an appropriate environment. Overall, the schools that responded to a JLARC staff survey estimated that 59 percent of students with ASDs or suspected ASDs are in a general education classroom for most of the day, and most of these students receive specialized supports in that setting. Survey analysis shows that "inclusion" is the preferred intervention of 33 percent of schools and is regularly used by 91 percent. Further, nearly two-thirds of caregivers who responded to a staff survey agreed that school services were provided in the most suitable setting for their child and that adequate opportunities were given for inclusion in classroom settings with non-disabled peers. In addition, most caregivers (82 percent) indicated being adequately involved in the development of their child's IEP.

Schools' Ability to Address Core Deficits of ASDs Is Mixed

While there is no one curriculum that is appropriate for all students on the autism spectrum, students with ASDs generally have impairments in behavior, social skills, sensory abilities, communication skills, and cognition. Schools must be able to address these core impairments in order to minimize special education services and maximize students' future independence. Most respondents to the JLARC staff survey of a sample of schools reported either a "high" or "moderate" ability to address these domains of functioning for students with ASDs (Figure 17). However, three-quarters of respondents to a JLARC staff survey of caregivers indicated that schools were unsuccessful at improving their child's social or sen-

Figure 17: Approximately Half of Schools Responding to Survey Report a "High Ability" to Address the Core Deficits of ASDs



Source: JLARC staff survey of a sample of Virginia public schools, February 2009.

sory abilities, and approximately two-thirds reported that schools did not successfully address their children's communication, cognitive, or behavioral needs.

While research on educating children with ASDs stresses the importance of providing services in a way that promotes students' ability to "generalize" positive changes in their functioning to multiple environments, most schools (75 percent) reported an inability to consistently provide services that would meaningfully improve students' functioning in non-school settings, such as the home or community. A lower percentage of schools in more rural areas of the State reported an ability to promote generalization. Nearly forty percent of caregivers who responded to a staff survey reported that schools exhibited a "poor" ability to provide services to improve their child's functioning at home or in the community.

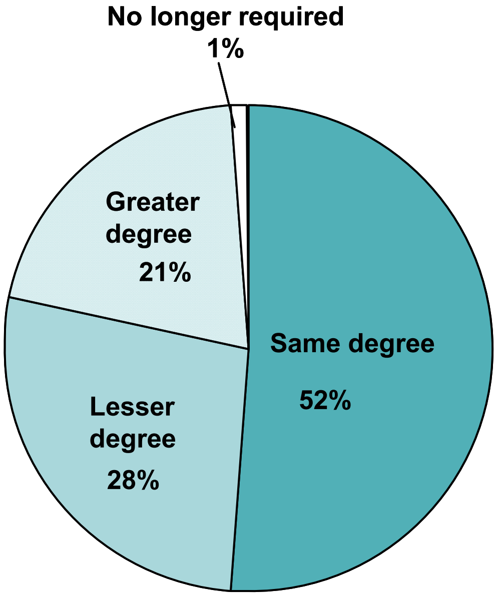
Most Students With ASDs Require As Much or More Special Education Services Over Time, Based on a Sample of Schools Surveyed

While research on interventions for children with ASDs indicates that many children who receive effective services at a young age will require fewer special education services and supports over time, this does not occur for most Virginia students with ASDs. Nearly 40 percent of elementary schools responding to the JLARC staff survey reported being unable to provide students with ASDs services that will minimize the need for future special education services at least "most of the time." Among students with ASDs who have been receiving special education services for at least a year, 73 percent require the same or a greater level of services than when services were first initiated by the school, based on a JLARC survey of a sample of Virginia schools (Figure 18). Schools in more urban areas of the State reported a higher percentage of students who required a greater level of services over time. Additionally, 64 percent of caregivers reported that their child required as many or more specialized services over time. However, many factors likely influence changes in the degree of special education services students with ASDs require over time, including the extent to which they have reached their highest potential level of functioning and parents' refusal to reduce services.

EFFECTIVE EDUCATION FOR STUDENTS WITH ASDs INCORPORATES RESEARCH-BASED INTERVENTIONS AND STRUCTURE

Effective programs for students with ASDs appear to rely on the use of interventions and programming structures that are research based. Both Congress and the National Research Council (NRC)

Figure 18: Most Students With ASDs Require As Much or More Special Education Services Over Time



Source: JLARC staff survey of a sample of Virginia public schools, February 2009.

emphasize the importance of using interventions that are based on sound research and have been proven effective. IDEA requires that IEPs include services that are "based on peer-reviewed research, to the extent practicable." It is in the student's best interest to participate in research-based programs, and it is also in the public's best interest for schools to invest resources in strategies that are most likely to be effective. As described in Chapter 2, numerous interventions and methodologies have been developed to address the key problem areas of ASDs, but few have been shown to be empirically effective, and even that evidence is limited in some cases.

Effective programs for students with ASDs will ensure that teachers and related services staff are competent in identifying and correctly implementing research-based interventions that have the desired effects on students' short-term functioning and long-term independence. In 2001, the NRC identified research-based approaches for educating students with ASDs and concluded through its review of ten state-of-the-art programs that there is "a consensus…on the factors that result in program effectiveness." While the programs reviewed are targeted at children age eight and younger, some of the common elements appear applicable for educating older children as well, including

- highly trained staff who specialize in ASDs,
- ongoing assessments of students' progress, and

- teaching procedures that emphasize the generalization and maintenance of skills.

RESPONDENTS REPORT THAT APPROACHES TO MEETING NEEDS OF STUDENTS WITH ASDs VARY WIDELY AND DO NOT ALWAYS INCLUDE RESEARCH-BASED INTERVENTIONS

Virginia's schools use a wide variety of educational interventions and strategies for students with ASDs, based on JLARC staff site visits and an analysis of a JLARC staff survey. The types and intensity of services offered to students with ASDs depends on each school's, or even each classroom's, approach to service provision, which does not always incorporate research-based practices. One of the most striking differences between the schools visited by JLARC staff were the opposing philosophies held with respect to specific interventions or even general practices. State-level efforts to improve the uniformity and consistency of schools' approaches to ASD service provision are currently underway.

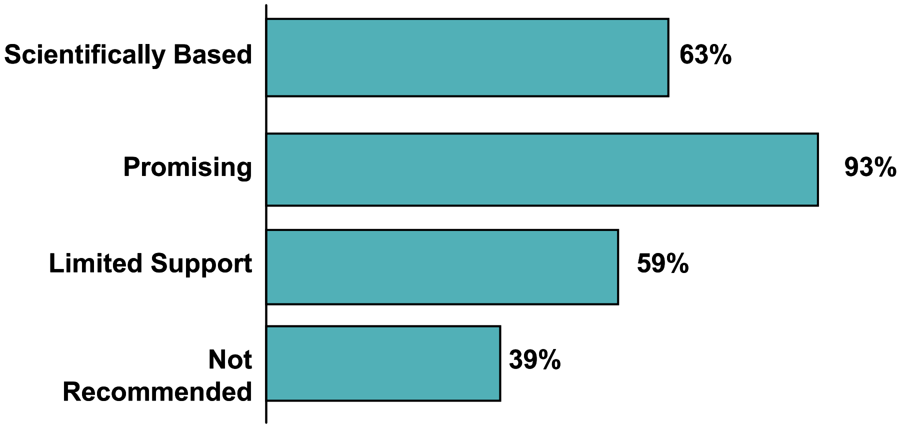
Nearly Half of Responding Schools Do Not Regularly Use Scientifically Based Interventions, But Most Use Promising Practices

Despite the emphasis placed on research-based interventions in both the literature and special education law, Virginia schools appear to not consistently use practices that have been proven effective among students with ASDs. Students with ASDs generally receive a combination of services that are generic and ASD-specific. The most frequently reported interventions used by schools for students with ASDs are generic, such as speech therapy (87 percent), positive behavioral supports (80 percent), and occupational therapy (79 percent), which are generally considered effective.

More than one-third of schools responding to the survey reported regularly using interventions that Simpson categorized as "not recommended."

Most schools reported regularly using interventions categorized by Richard Simpson in 2005 as "promising" for students with ASDs, and nearly two-thirds regularly use practices identified as "scientifically based" (Figure 19). As described in Chapter 2, scientifically based practices are characterized by "significant and convincing empirical efficacy and support." In addition, more than one-third of schools responding to the survey reported regularly expending their limited resources on interventions categorized as "not recommended" for students with ASDs, and this practice was reported more often by elementary schools (41 percent). Examples of interventions used by schools that are considered "not recommended" include holding therapy and facilitated communication. Importantly, analysis of responses to the staff survey shows that schools using interventions characterized as either "scientifically

Figure 19: More Than One-Third of Respondents Use At Least One ASD-Specific Intervention Not Recommended by Experts



Note: Percentages reflect the proportion of responding schools using at least one intervention falling into any of the above categories.

Source: JLARC survey of a sample of Virginia public schools, February 2009.

based" or "promising" are better able to meet the needs of students with ASDs.

Specific "Packaged" Interventions Appear More Promising, but Many Schools Use the Mixed-Methods Approach

Because individualized educational programming often necessitates the use of multiple instructional strategies, Virginia schools commonly rely on a variety of approaches to serve students with ASDs. However, only a minority of schools report using comprehensive packages such as applied behavior analysis (ABA). Further, fewer than ten percent of schools use these packages as their preferred intervention, relying instead on a "mixed methods" approach to meeting the needs of students with ASDs, despite evidence that packages tend to yield better results (Chapter 2). The literature does note that a mixed methods approach could be just as effective as a package, in theory, but that it requires a degree of expertise, planning, and coordination that is often not present in Virginia schools.

The use of a mixed methods approach in many Virginia schools may be reinforced by several factors. DOE appears to support this approach, and DOE staff have thus far been reluctant to identify which, if any, comprehensive packages schools should consider. According to DOE staff, the agency is "making a point to steer clear of any [specific] methodologies" because schools tend to "overuse" a strategy for all students, and school staff are thus unable to determine what strategies will work best for a student's individual needs. DOE's stance appears to be consistent with that of the federal DOE and the NRC, which also do not address whether or which packages should be used. Additionally, interviews with school staff and ASD experts suggest that many school personnel lack expertise in implementing comprehensive ASD-specific packages. Lastly, packages can also be more costly to implement given the proprietary nature of some material.

In some cases, reluctance to use a particular methodology appears to stem from misconceptions about the nature of particular interventions. For example, it appears that part of the reluctance to apply ABA-based therapies is due to confusion about the nature of ABA, which practitioners often mistakenly equate with regimented "discrete trial training." Such misconceptions may result in hindering some students' access to interventions that may be most effective for them. However, because ABA-based strategies encompass a very broad assortment of interventions, DOE staff have theorized that many schools are in fact regularly using these strategies without realizing it.

DOE Provides Information to Schools on Research-Based Interventions for ASDs, Yet Schools Report Needing More Practical Guidance

Part B State Performance Plan

IDEA requires each state to develop a plan that evaluates implementation of Part B of the act and describes planned improvements. States report on their performance with respect to targets established in the plan, such as the amount of time students with IEPs spend in a regular classroom.

DOE has taken several steps to provide guidance to schools on the use of research-based practices for students with ASDs. However, many schools appear unable to confidently identify research-based interventions and instructional strategies for these students. In fact, 31 percent of schools responding to a JLARC staff survey cited the lack of State guidance as a training and technical assistance challenge that undermines their ability to serve students with ASDs. Given the multitude of approaches that are touted as effective for students with ASDs, teachers would benefit from access to information that allows them to separate sound practices from ineffective ones. Yet, according to DOE staff, the primary guidance that has been widely distributed consists of the 2005 Simpson article referenced above, which does not address how to match research-based interventions to a student's particular needs or how to accurately apply these interventions. DOE's ability to provide widespread practical guidance is limited by the fact that the agency only has one-third of a staff position dedicated to ASD services.

DOE has recently undertaken several initiatives to improve schools' knowledge of research-based practices for ASDs. As part of the federally required State Performance Plan for special education, DOE initiated the Autism Priority Project in 2006. According to a project member, one of the objectives of the Priority Project is to determine the degree of effectiveness for the various interventions and strategies that have been promoted for students with ASDs. This information is communicated to schools through biennial meetings of designated division-level representatives, many of whom serve as the division's "autism specialist." However, designees' level of knowledge about ASDs varies and DOE does not have a mechanism to ensure that the information conveyed at these meetings is correctly communicated back to individual school personnel. Moreover, according to DOE staff, one-quarter of Virginia's school divisions have not sent a representative to these meetings. Additionally, the NRC has deemed these types of training efforts as inadequate if not paired with "multiple exposures, opportunities to practice, and active involvement in learning."

DOE also provides ongoing support to ASD "train-the-trainer" teams in 20 divisions that act as division-level training and consultation staff. According to DOE, between September 2008 and March 2009, these teams provided 459 training events which reached nearly 4,000 individuals across the State. The NRC recommended that the concept of "train-the-trainer" teams be incorporated into states' professional development programs for ASDs.

In addition, DOE is currently drafting a handbook to guide schools' practices for educating students with ASDs. While the content of DOE's guidelines had not been finalized at the time of this study, DOE staff indicated that they will include information on the array of research-based practices for students with ASDs. Unlike prior guidance, the handbook is expected to provide comprehensive and consistent information that will be available to all schools.

PROFESSIONAL DEVELOPMENT OPPORTUNITIES DO NOT ADEQUATELY ADDRESS NECESSARY COMPETENCIES

Despite an array of professional development opportunities, many Virginia school personnel remain inadequately trained to meet the needs of students with ASDs. The majority of schools report that inadequate preparation undermines personnel's ability to meet the needs of students with ASDs. Existing professional development initiatives are provided through multiple public and private entities, but these efforts are not coordinated and trainings are often crafted without a comprehensive understanding of schools' needs. While school staff can supplement their knowledge by accessing experts, they are not uniformly available to all divisions. In addition, neither new nor existing school personnel are required to possess the competencies that have been identified as necessary to serve students with ASDs, or to obtain a certificate demonstrating their skills.

Virginia School Personnel Are Often Inadequately Trained to Meet the Needs of Students With ASDs

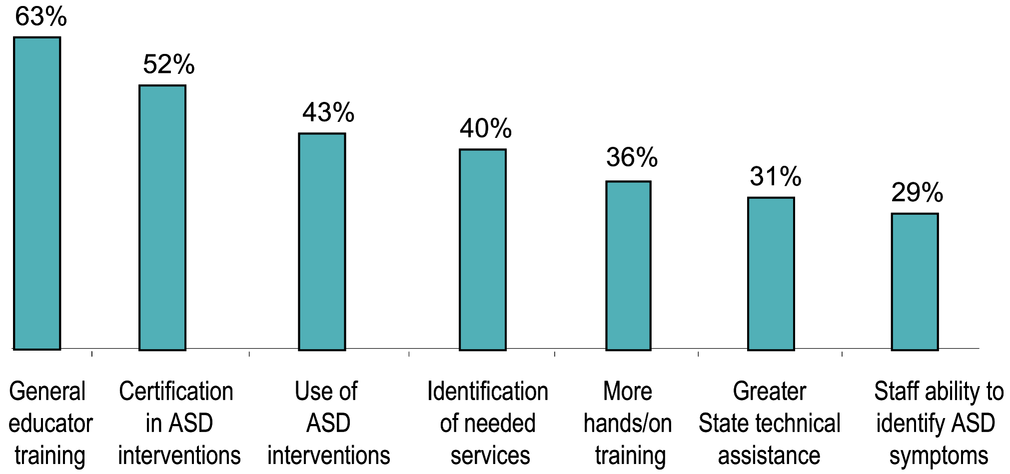
Inadequate training was the most frequently cited challenge to meeting the needs of students with ASDs.

Inadequate training was the most frequently cited challenge to meeting the needs of students with ASDs on a JLARC staff survey of a sample of Virginia schools. The top training need identified by schools is greater preparation for non-special education ("general education") teachers who serve students with ASDs (Figure 20). In addition, more than one-third of schools reported that their inability to identify appropriate ASD-specific interventions was a moderate or significant challenge to meeting the needs of these students. While knowledge of research-based practices for students with ASDs is a critical component of effective educational programming for these students, it is also essential that classroom teachers have the expertise to implement these practices accurately. More than half of survey respondents identified the lack of certification in ASD interventions among school personnel as a significant or moderate challenge, and 43 percent reported needing further knowledge about properly administering ASD-specific interventions. Simpson writes that "without treatment fidelity, wherein methods are correctly, consistently, and carefully implemented…even the most effective technique will likely be unable to deliver expected outcomes."

Schools' Access to Professional Expertise in ASDs Does Not Consistently Meet Needs

Schools do not appear to consistently have access to ASD experts who can supplement the knowledge of their staff. Site visits and

Figure 20: Schools Report Multiple Training Needs



Source: JLARC staff survey of a sample of Virginia public schools, February 2009.

survey results indicate that school personnel possess varied levels of knowledge about ASDs and effective teaching strategies. To bridge knowledge gaps, the NRC recommends that states create training and technical assistance programs that include professionals with special ASD expertise who can assist schools as needed. However, Virginia's training and technical assistance programs do not appear to consistently offer access to ASD expertise either in-house or through external channels. In particular, the State's network of technical assistance centers does not appear to provide the type and intensity of services that schools report needing. Although some school divisions have built local expertise, this is not the case statewide.

T/TACs' Capacity to Meet Training Needs May Be Insufficient. Through its seven special education Training and Technical Assistance Centers (T/TACs), DOE has created a regional organization for supporting schools and classroom teachers in educating students with all types of disabilities. Five of the centers provide ASD-specific support services. Many school staff interviewed by JLARC staff expressed satisfaction with their services. However, as one special education director stated, while T/TACs "fulfill their mission above and beyond…their mission is not to do everything that we need." Notably, due to resource constraints, T/TACs do not have staff who are dedicated solely to providing technical assistance and training on ASDs; instead, T/TAC staff who are responsible for providing ASD services are also responsible for other disability categories. Further, JLARC staff found that only one T/TAC staff person across all seven T/TACs is professionally certified in an intervention that is considered effective for students with ASDs, although most T/TAC staff reported significant experience in working with ASDs and training in ASD-specific interventions such as Picture Exchange Communication System. Although the T/TACs may be of great assistance, they appear to lack the resources and ability to provide the scope and intensity of professional development that could most benefit schools.

During interviews, school personnel often reported needing more intensive and hands-on training, an issue which more than one-third of survey respondents identified as one of their most pressing challenges. T/TACs provide on-site consultation services that assist schools and IEP teams in meeting the needs of specific children, but the frequency of these on-site consults has been decreasing as T/TACs have had to balance the demand for this more resource-intensive, school-specific assistance with the more efficient approach of delivering training to larger audiences. Even when conducting on-site consults, T/TAC personnel interviewed by JLARC staff reported that their role is not to act as a school's expert for determining how best to serve an individual student, but rather to give school staff the information necessary to make these determinations themselves. Rather than provide specific recommendations to schools for how to address the needs of a challenging student, all T/TAC staff interviewed by the study team reported that they will give schools a list of "considerations" for guidance. It should be noted that regardless of the type of guidance or recommendations T/TACs offer to schools, T/TAC staff do not serve on a student's IEP team, which is ultimately responsible for determining the services and supports the student will receive from the school.

Many Virginia School Districts Took the Initiative to Create Local-Level Expertise in ASDs. Survey results indicate that 59 percent of school districts have designated a staff person to serve as the division's "ASD specialist" to provide support and expertise to classroom teachers, and this is a resource that is more common in urban areas of the State. Site visits indicate that the amount of expertise possessed by ASD specialists and the specific roles that they play vary statewide. However, an analysis of the JLARC staff school survey results shows that schools with access to an ASD specialist often report a greater ability to meet the needs of students with ASDs. For example, schools with an ASD specialist had fewer students who required a higher degree of special education services over time and a greater number of schools with an ASD specialist reported being able to optimize the educational potential of students with ASDs. Approximately 50 percent of schools cited insufficient access to an ASD specialist as a technical assistance challenge that undermines their ability to serve these students, and this was the case statewide.

Additionally, several school districts have forged partnerships with private-sector ASD experts. For example, 22 school divisions currently have ABA-certified staff from Commonwealth Autism Service (CAS) embedded in their classrooms, and CAS staff reported that there are 18 other school divisions on their waiting list for services. A few other divisions work with staff from the Faison School for Autism located in Richmond. These experts provide hands-on support in special education classrooms by evaluating teaching techniques and demonstrating effective practices for working with students with ASDs. The school divisions that use these partnerships report a high degree of satisfaction with the training and technical assistance provided at the classroom level. One school division reported that its partnership with the Faison School has allowed it to bring students with ASDs who were in costly private placements back into the public school system. However, despite the success of the partnerships in several school divisions, the State does not appear to actively promote or coordinate this model.

Interviews with school staff around the State revealed that several school divisions have formed regional special education programs to enhance their ability to meet the unique needs of students with ASDs by combining resources and expertise. Site visits indicated that some regional special education programs were better able to bring in additional ASD-specific expertise for use in their schools, create training opportunities to improve the competencies of their school personnel, and plan strategically at the administrative level for improving the quality of their ASD-specific services. Regional models have also reportedly allowed some school divisions to avoid costly private educational placements. In addition, while the protocols and structures of regional programs vary, survey respondents that have access to this resource were more likely to report the ability to optimize the educational potential of these students and to improve their behavior and social functioning in settings outside of school compared to schools without access to a regional program.

In-Service Training May Not Adequately Build ASD Expertise Among School Personnel

An attempt has been made in Virginia to identify the qualifications needed by school personnel who work with students with ASDs, although the extent to which this information has been used is unclear. A major accomplishment of the Virginia Autism Council (VAC) is the recently developed "Skills Competencies for Professionals and Paraprofessionals in Virginia Supporting Individuals with Autism Across the Lifespan" ("skills competencies"). The skills competencies are intended to be used by all service providers, including school personnel. The document outlines six key areas in which providers should be proficient, based on an extensive review of best practices for educating children with ASDs. DOE recently developed a companion "professional development tracker" tool for school personnel to identify their possible weaknesses with respect to the various competencies. While the skills competencies are a useful guide to identify knowledge deficiencies and focus training efforts, schools are not required to use them.

To build these competencies, the VAC has been involved in identifying and disseminating information about available training opportunities. Most significantly, in 2006, the VAC created an incentive program to recognize college and university training programs that offer coursework leading to ASD certification. The VAC offers partial tuition reimbursement for ASD certificate programs offered to both existing and future teachers in seven Virginia colleges and universities (Table 24). The coursework in these programs is designed to develop basic awareness and knowledge about ASDs, as well as to provide more in-depth training on instructional strategies and working with students with ASDs. In order to be a recognized certificate program, the curriculum must include instruction in 80 percent or more of the skills competencies elements, nine to 12 credit hours, and a minimum of 15 hours of “field experience.”

To improve the ability of school personnel to educate students with ASDs, Virginia school divisions have frequently relied on workshops, conferences, and online training. The VAC has also been involved in identifying and disseminating information about relevant training opportunities. However, schools that responded to a staff survey indicated that a lack of support for attending training was a challenge. In addition, as mentioned above, the NRC has deemed these types of training efforts as inadequate on their own.

Table 24: Virginia Colleges and Universities Offering ASD and Behavioral Analysis Certification Programs

College or University	Certification	Location
George Mason University	Behavioral Analysis	Fairfax County
Longwood University	ASD	Farmville City
Lynchburg University	ASD	Lynchburg City
Old Dominion University	ASD	Norfolk City
Rappahanock Community College	ASD	Richmond County
Regent University	ASD	Virginia Beach City
University of Mary Washington	ASD Behavioral Analysis	Fredericksburg City
Virginia Commonwealth University	ASD	Richmond City

Source: JLARC staff analysis of information maintained by the Virginia Autism Council.

Pre-Service Training Is Not Consistently Offered to Prepare New Teachers for Educating Students With ASDs

While ASD-specific coursework is available in several Virginia universities, interviews with school personnel indicated that special education and general education teachers seldom begin their teaching careers with knowledge about the education of students with ASDs. Special education staff at two school divisions reported that the bulk of ASD professional development consisted of informal learning on the job. As described above, seven universities offer a certificate program in ASDs, which could serve to better prepare special education teachers interested in the field of ASDs. Data are not available on the number of individuals who have received or are currently pursuing certification. However, the university personnel who provided input indicated that future teachers have a high level of interest in the certification program. Yet, anecdotal reports suggest that only a small segment of teachers have taken advantage of the certification opportunity, which may be partially due to the absence of salary increases or other incentives that accompany certification.

Two Virginia universities (Mary Washington University and George Mason University) also offer coursework leading to certification in behavioral interventions that could benefit students with ASDs. Sixty-four percent of JLARC school survey respondents reported having either a behavioral specialist or a certified behavioral analyst on staff to serve students with ASDs. However, Virginia does not require or provide incentives for school personnel to be certified in the provision of behavioral interventions. As with the ASD certificate, the State does not provide additional compensation to school personnel who are certified in behavioral interventions. According to the Autism Special Interest Group of the Association for Behavior Analysis, certification in behavior analysis demonstrates that an individual has met minimum competency standards, but does not guarantee that he or she has "specific expertise in the treatment of autism."

Pre-service ASD training opportunities are reportedly lacking for general education teachers. Schools reported to JLARC that the primary training and technical assistance challenge they face in meeting students' needs is the lack of training provided to general education teachers about ASDs. School personnel interviewed during site visits also reported that basic training on behavior management was sorely needed and should be required of individuals studying to become general education teachers.

NO UNIFORM MEASURE OF PROGRESS FOR STUDENTS WITH ASDs

Although setting measurable goals has been identified as a best practice by the NRC and is required by both IDEA and DOE regulations, Virginia schools do not appear to consistently collect the information needed to ensure the effectiveness of selected interventions. Student progress may be measured relative to a student's Individualized Education Program (IEP) goals and objectives, which tend to be longer term, as well as daily goals tied to classroom activities. However, there is no specific requirement for schools to reliably track students' progress, and some school personnel may lack the knowledge to set appropriate goals. As a result, schools and families frequently rely on subjective impressions to define progress.

IDEA and DOE require that IEPs for all students include measurable goals and objectives related to their education. The NRC emphasizes the importance of linking IEP goals to daily activities and frequently measuring the progress of students with ASDs toward achieving the goals and objectives outlined in their IEP. According to the NRC, "ongoing measurement of educational objectives must be documented in order to determine whether a child is benefiting from a particular intervention." Further, the NRC recommends that “every child’s response to the educational program should be assessed after a short period of time.”

Interviews with school and DOE staff suggest that school personnel have limited capability to record meaningful measures of students’ progress, and consequently to use these data to alter program goals and objectives. Additionally, schools are only required to review IEPs annually. While school staff indicated performing more frequent reviews when needed, it does not appear that progress toward IEP goals is consistently measured as frequently as recommended by the NRC. Further, neither State regulations nor guidance address how to measure progress, analyze data, or use the data to improve a child’s educational program.

At this time, while DOE has developed a model IEP for schools to use at their discretion, the agency has not provided guidance on best practice techniques for developing IEPs specifically for students with ASDs. Moreover, DOE has not prioritized the importance of tracking students’ progress by frequently recording quantifiable data for students with ASDs. While some DOE-supported efforts to improve teachers’ ability to quantify students’ progress have been recently undertaken – such as a training provided to ASD specialists on data collection and IEP development – these do not yet appear to have appreciably improved teachers’ skills statewide. To the extent that educational programming can be made more cost effective through data-driven decision making, schools should receive the tools and training to collect and report this data in a uniform and consistent fashion. In addition to providing IEP teams with the information needed to make “mid-course” corrections to a student’s educational program, communication with parents could be improved by using data to measure student progress, and by extension the effectiveness of school services.

In addition to measuring student progress against IEP goals and objectives for students with ASDs, measuring performance against more immediate goals also helps to ensure the effectiveness of selected interventions. Of the ten “model programs” reviewed by the NRC, all had some way of tracking children’s progress. For example, the behavioral programs relied on teacher-recorded data that was taken daily and reviewed weekly. At least two school divisions visited by JLARC staff have taken steps to develop their schools’ capacity to use data to measure the progress of students with ASDs. Albemarle County schools, for example, contracts with the Virginia Institute for Autism for training on how to measure students’ progress. These school staff reported that they are implementing a program to monitor children’s reactions to specific interventions on a weekly basis.

VIRGINIA STUDENTS WITH ASDs MAY NOT RECEIVE SUFFICIENT PREPARATION FOR ADULTHOOD

The ultimate goal of school services for students with disabilities, including ASDs, is to prepare them to live with some degree of independence once they are no longer eligible for school services, to the extent that the nature and severity of their disability allows. IDEA requires schools to equip students for further education, employment, and independent living, but it appears that Virginia schools often lack the ability to adequately transition individuals with ASDs to post-school life. Preparation for independent living is considered by the NRC to be a hallmark of effective educational programming for students with ASDs.

Almost half (47 percent) of high schools reported having a "moderate" or "low" ability to address the social skills of students with ASDs.

Building social, life, and vocational skills is critical for students with ASDs to achieve any measure of independence, but results of a JLARC staff survey of a sample of public schools suggest that schools' ability to foster these skills is limited. Almost half (47 percent) of high schools reported having a "moderate" or "low" ability to address the social skills of students with ASDs. Further, most schools (71 percent) reported being unable to provide services that maximize the future independence of all of their students with ASDs. Additionally, caregivers reported in another JLARC staff survey that insufficient vocational and job skills training in high school (43 percent) as well as a lack of preparation for getting and keeping a job (27 percent) were key barriers to independence for their children. These results appear to be attributable, in part, to a transition process that does not consistently address the specific needs of students with ASDs, and to insufficient resources to provide life and vocational skills. While individuals with disabilities face unique barriers to gainful employment in any economic climate, current economic conditions further exacerbate their difficulties and give added urgency to the need for schools to provide more practical vocational and job skills training.

Transition Planning May Not Consistently Meet Students' Needs

While DOE has taken promising steps toward improving school personnel competencies on transition services through the Transition Priority Project, this initiative does not distinguish the potentially unique transition needs of students with ASDs from those of students with other disabilities. The core deficits of ASDs that impact a student's education are equally likely to impact the student's preparation for transition. For example, students with ASDs are more likely to require transition planning that takes into account their characteristically limited social skills.

The notion that students with ASDs face different and, at times, greater barriers to transition is supported by the fact that they appear to experience less favorable outcomes than students with other disabilities. Based on a DOE survey of special education students who had graduated in 2007 and who had been out of school for one year, it appears that, among students who were employed, a higher percentage of students with ASDs were employed part-time (75 percent) than the group as a whole (41 percent). Moreover, a greater proportion of students with ASDs worked for minimum wage or less (32 percent) compared to all students with disabilities (18 percent). Among students pursuing post-secondary education, those with ASDs were also less likely to be enrolled full-time. This suggests that knowledge about the specific needs and characteristics of students with ASDs should be incorporated into the transition process to help students achieve their full potential for future employment or post-secondary education.

To implement transition plans, which may involve identifying and coordinating community-based opportunities for developing life and vocational skills, schools also need access to personnel who have expertise in transition planning and services. In a staff survey of a sample of schools, 24 percent of high schools reported that a lack of dedicated transition staff is a significant or moderate challenge to their ability to meet the needs of their students with ASDs. In fact, because not all school districts have a staff person devoted exclusively to transition services, special education teachers are reportedly often responsible for arranging for vocational training or job coaching through local employers. However, special education teachers may not have sufficient time or expertise to effectively serve in this capacity. DOE staff identified having a division-level staff person dedicated, at least part-time, to transition services as a resource that is needed to ensure proper planning and implementation.

Services to Prepare Virginia Students With ASDs for Post-School Life Are Limited

Many schools appear to lack the services needed to prepare students with ASDs for adulthood. High schools identified the lack of resources to provide life skills and vocational training instruction to students with ASDs as the top challenge related to transition, according to the JLARC staff survey of a sample of public schools. Forty-seven percent of high schools identified resources to provide either life skills or vocational skills as a challenge, and 38 percent cited both. While the State has begun to focus on improving the planning phase of students' transitions through its Transition Priority Project, efforts have not yet addressed building schools' capacity to provide services that promote students' ability to function as independently as possible after the transition has occurred. According to DOE staff, schools vary in their ability to implement life skills or vocational training programs for special education students. In the past, schools offered "Education for Employment" classes in which students split their time between a classroom and a job, but these classes are now seldom available. It appears that responsibility for developing life or vocational skills programs now rests with individual school divisions. In addition to resource constraints, school personnel explained during site visits that fitting life and vocational skills training into the schedules of students with ASDs could also be a challenge, given competing instructional priorities, such as the Standards of Learning. There are no requirements for students with disabilities, including ASDs, to take such classes.

OPTIONS TO BETTER MEET THE NEEDS OF SCHOOL-AGE VIRGINIANS WITH ASDs

JLARC staff have identified several options that the State could consider to improve the skills of school personnel in developing and implementing educational plans for students with ASDs and providing services that maximize their future independence. These options vary in terms of the resources and time needed for implementation as well as their impact on the issues described in this chapter. In several cases, the State or other entities have already laid the groundwork for implementing these options through existing initiatives or programs. These options could help ensure that school services for students with ASDs are delivered in a manner that is consistent with federal and State laws and regulations regarding the provision of a free and appropriate public education in the least restrictive environment. These options could also generate additional resources and supports for school personnel, students, and families alike. Many of these options have the potential to improve the quality of school-based services for all students with disabilities, not just those with ASDs.

Implementing Options Would Require Greater Involvement and Oversight From DOE

Currently, DOE dedicates one-third of a staff position to the role of State autism specialist, which seems incongruent with the amount of policy guidance, oversight, and expertise demanded by this complex and challenging area of responsibility.

To facilitate the implementation of many options discussed in the remainder of this chapter, DOE would need to enhance its professional development and oversight capabilities, which would likely necessitate additional staff. Currently, DOE dedicates one-third of a staff position to the role of State autism specialist, which seems incongruent with the amount of policy guidance, oversight, and expertise demanded by this complex and challenging area of responsibility. Although school divisions should retain discretion in their educational programming, DOE could take a more proactive role in establishing guidelines and providing expert assistance to school divisions. In particular, additional State-level staff could develop and disseminate ASD service guidelines; assist in creating adequate technical assistance and training programs; keep abreast of current research on practices for educating students with ASDs; and coordinate DOE's efforts with other agencies and stakeholders.

Additional Guidance Could Be Provided on Research-Based Practices

While resource variations and other factors will always result in schools using different approaches, parents, students, and school personnel alike would benefit from having a common understanding of schools' responsibilities for educating students with ASDs and the most effective means of meeting their educational needs. In particular, statewide guidelines could remove unwarranted inconsistencies in the education of children with ASDs. DOE is currently developing guidelines to be used by schools in designing and implementing the educational plans of students with ASDs. Connecticut and Ohio have reported successful implementation of their ASD service guidelines, which could serve as models for Virginia. In addition, the National Professional Development Center on ASDs, a university-based program supported by U.S. Department of Education, has defined research-based practices for ASDs and has resources to help states introduce these practices to school districts. Further, the National Autism Center is due to release standards for "effective, research-validated education and behavioral interventions for children with ASDs" in 2009.

To address the inconsistencies noted earlier in this chapter, DOE could, at a minimum, address the following items:

- identify the pool of research-based practices for educating students with ASDs which schools should draw from;
- specify that services be delivered in a way that promotes generalization;
- clarify that schools need to focus on improving students' social skills, and identifying effective interventions to this end, regardless of students' academic abilities;
- emphasize that students be given opportunities to learn basic life skills before they exit school; and
- incorporate the VAC's research-based skills competencies for service delivery.

Because new research is continually being conducted, DOE could revise the guidelines as needed. In addition, to ensure that these guidelines result in a more uniform and effective approach to educating students with ASDs, DOE could distribute them to every public school and provide statewide training on their contents through the T/TACs.

DOE could also use the ASD service guidelines to address the merits of using comprehensive programs versus mixed-methods approaches for individual students. As discussed previously, while comprehensive programs have been shown to be more effective, they could also be more costly to implement given the proprietary nature of some of the material. Another drawback could be the challenge of identifying which package will work for individual students, given the complexity of students' needs as well as the often limited evidence about the effectiveness of each available approach. Instead, it may be more helpful for DOE to identify what elements of each of the research-based comprehensive programs are effective for specific behaviors or deficits caused by ASDs so that schools have adequate information to effectively create mixed-method interventions for particular students.

Professional Development Programs Could Be Enhanced

The State could undertake several complementary efforts to create a more integrated and effective statewide professional development programs for school personnel. The State has already initiated several professional development initiatives that could be leveraged to improve schools' access to expertise in educational programming for students with ASDs. Additionally, many school divisions have undertaken promising initiatives that the State could expand upon to better serve students with ASDs. By ensuring that schools have the resources, expertise, and planning capabilities needed to implement effective educational programming for students with ASDs, the State would not only improve the outcomes of students with ASDs, but also potentially improve the extent to which students can be educated in their home schools and avoid costly private educational placements. The major advantages and disadvantages associated with each option are listed in Table 25.

Improve Access to In-Service Professional Development Opportunities. The State could add professional development hours to the existing time designated for in-service training to allow teachers to attend ASD-specific training opportunities. The State could also create an electronic clearinghouse of ASD-specific training materials used by the T/TACs, the VAC, or other entities to ensure that all school personnel have equal access to these materials. Several school personnel reported that lack of access to in-service training opportunities and materials has been a barrier to becoming more competent in teaching students with ASDs.

Table 25: Advantages and Disadvantages of Options to Enhance Professional Development Programs

Options	Advantages	Disadvantages
Improve Access to In-Service Training		
Increase professional development time	Allows for training during work day Improves access to hands-on training	Reduces time school personnel spend in the classroom with students Increases need for substitute teachers
Develop electronic training materials	Improves access to training Available to all types of providers	May not include all training material Lacks benefit of hands-on and follow-up
Increase Professional Qualifications of Teachers		
Require newly hired teachers to attend training	Ensures new hires have ASD knowledge Improves skills uniformity	Requires additional staff development time
Require certification for special education teachers	Ensures consistent expertise Expands certificate programs	Not efficient use of resources May exacerbate existing recruiting challenges Requires time for additional coursework
Provide incentives for certification	More flexible than requirement Not detrimental to recruitment	Less apt to increase certificate programs or course offerings Less apt to uniformly improve skills
Require minimum coursework for special and general education teachers	More flexible than requirement Expands ASD coursework Promotes inclusion opportunities May reduce need for 1:1 aides	May exacerbate recruitment challenges Requires time for additional coursework
Provide incentives for minimum coursework	Greater flexibility than requiring minimum coursework or certification	Less apt to increase course offerings Less apt to substantially improve uniformity of teachers' skills
Require minimum number of teachers per division with ASD certification	Improves access to in-house resources and support	May cluster students, which could limit opportunities for inclusion
Improve Access to ASD Experts		
Identify model schools	Uses existing resources and expertise of schools Potential use for several topics More conducive to intensive training modalities Provides example for schools	Schools could become magnets for students with ASDs Possible increase in resources needed to make schools accessible for observation
Expand train-the-trainer	Uses local resource Builds upon existing resources Creates larger cadre of trained professionals	Challenging to ensure consistency across numerous teams
Enhance T/TAC expertise and training intensity	Uses current infrastructure Creates regional structure of accountability and expertise Provides liaison between DOE and schools Provides support for division-level experts Ensures consistency and uniformity across the State	Need resources to hire more qualified staff or train existing staff Changes T/TAC mission

Create division-level ASD experts	Based on existing infrastructure More efficient than every teacher possessing equal expertise Improves uniformity of access to information and support, such as behavioral expertise Behavioral analysis qualifications could benefit other disabilities Supports early intervention services	May be inefficient for divisions with fewer students Positions could be difficult to fill
Identify and Prioritize Training Needs		
Assess teacher competencies	Provides baseline data on personnel skills Identifies training priorities	Could be used in litigation
Develop regional training consortia	Accounts for unique local needs and resources Promotes strategic planning Promotes collaboration/pooling of resources Creates local liaisons for State efforts Identify unique local problems/solutions Multidisciplinary	Resource-intensive at the local level State oversight needed Smaller divisions may lack sufficient "critical mass"

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

New Jersey Requires Training in ASDs

In 2007, a new law was enacted in New Jersey that requires both pre-service and in-service teacher training in awareness and instruction methods for students with ASDs. This legislation applies to all teachers.

Increase the Professional Qualifications of Teachers. The State could improve the qualifications of its school personnel by targeting new teachers and/or building the skills of its existing workforce, both in special and general education classrooms. As mentioned previously, teachers seldom begin their careers with knowledge about the education of students with ASDs. Therefore, newly hired special education teachers could be required to complete ASD awareness training within their first year on the job. Because ASD awareness may not be sufficient to better meet the educational needs of children with ASDs, the State could require newly hired special education teachers to have taken a minimum number of ASD-related coursework hours on topics specified by the State.

Alternatively, the State could specifically require newly hired special education teachers to possess ASD certification which is currently available from seven colleges and universities in Virginia. If teachers were required to hold an ASD certificate, more universities would likely begin to offer a program. However, several Virginia school and State-level staff have expressed concerns that such a requirement could exacerbate existing recruitment challenges and special education teacher shortages. Instead, the State could provide incentives for new teachers to voluntarily increase their qualifications. For example, the State could grant full or partial tuition forgiveness for special education teachers who complete the ASD certificate. The State could also provide funding to pay ASD-certified teachers a higher salary.

To more immediately improve the expertise of school personnel, the State could also create incentives for current teachers to obtain ASD certification or take a minimum amount of continuing education coursework in ASDs. As with new teachers, existing special education teachers who hold qualifications in ASDs could be compensated at a higher rate than other teachers.

To ensure that schools have uniform capacity to meet the needs of students with ASDs, the State could require school divisions to employ a minimum number of special education teachers who have met ASD-specific coursework requirements. To meaningfully improve teachers' qualifications, these topics would not only need to include ASD awareness, but exposure to and knowledge of specific interventions that are considered evidenced-based for educating students with ASDs.

Lastly, options could be considered to better equip general education teachers to serve students with ASDs. As discussed previously, school staff interviewed by the study team as well as those responding to the JLARC staff survey reported that the lack of ASD-trained general education teachers was the single most important issue that the State should address for students with ASDs. The State could either require or offer incentives for newly hired general education teachers to complete a minimum number of coursework hours on ASDs, particularly behavior management. Improving the ASD-specific skills of general education teachers could promote the federal government's emphasis on inclusion and likely result in greater numbers of students with ASDs being educated alongside their non-disabled peers. Greater awareness could also ensure that general education teachers do not inadvertently undermine the progress that students with ASDs have achieved through their special education programming.

Improve Access to ASD Experts. To assist schools with limited inhouse expertise or access to external professionals, the State could identify model sites or lab schools that could be used as real-world examples for how to properly implement research-based interventions, provide effective social skills or life skills training, or demonstrate any of the core elements of effective educational programming for students with ASDs. As part of its efforts to partner with the National Professional Development Center on ASDs, DOE has already begun to identify model sites for the provision of ASD-specific services. The model site concept is promoted by the NRC.

DOE's ASD train-the-trainer teams are also a valuable training and technical assistance resource for basic ASD service delivery topics, and the State could offer financial incentives to expand these teams statewide. However, more intensive training that centers on how to properly use interventions would have to be assumed by a more formal entity, such as T/TACs.

The State could also enhance the expertise of T/TACs by ensuring that they are staffed with enough highly trained professionals who have the expertise to provide schools with intensive training. This training could include demonstration teaching or short-term classroom-based team teaching. California's Diagnostic Centers provide this type of intensive training to schools for their most challenging students, which commonly include those with ASDs. T/TACs could contract with existing providers, such as Commonwealth Autism Service, to provide services for which there is already expertise.

Lastly, the State could fund and require all school divisions to create positions for certified or at least highly trained professionals to provide full-time ASD support to schools. This option would expand upon the ASD specialist concept that has already been initiated in many divisions. Division-level ASD experts would represent another tier in the State's professional development programs and would be more efficient and effective than expecting all special education teachers to possess uniform and in-depth expertise on ASDs. School personnel who are unsure how to address the needs of a student with an ASD could contact their division-level expert for guidance. In especially challenging situations, both the school staff and the division-level expert could consult with their T/TAC. To ensure consistent staff capacity across divisions, the number of positions allotted would need to vary based on the number of students with ASDs in each division.

Michigan START

Michigan has developed the Statewide Autism Resources and Training (START) project to promote training for ASDs. The hallmark of the START program is a tiered approach to training and technical assistance in which the state's department of education oversees training that is provided at the regional, school level, and school levels specifically on educating students with ASDs. Strategic planning and collaboration occurs at both the regional and school district levels. School district teams also support building-level training provided by multidisciplinary training teams.

Identify and Prioritize Training Needs. The State has not identified ASD-specific training priorities, which has resulted in training opportunities that vary by topic, intensity, and method of delivery across school divisions. To create a statewide training agenda and focus on the most pressing issues, DOE could undertake an assessment of teachers' ASD competencies. The professional development tracking tool that was recently developed for school personnel to compare their own ASD knowledge to the VAC's skills competencies could be used by school divisions to collect this information. While this self-assessment tool is not intended to be used as a formal assessment of ASD knowledge and is currently voluntary, DOE could require that school divisions report aggregated results of teachers' self assessments.

Finally, the State could create regional consortia of multidisciplinary professionals to identify the training needs of school staff, develop annual training plans, facilitate the provision of training to schools, and conduct strategic planning for improving schools' ability to serve students with ASDs. Members of these regional consortia could include special education administrators, special education teachers, related services personnel, post-secondary transition specialists, and designated division-level ASD experts. Non-school stakeholders such as parents, early intervention staff, Department of Rehabilitative Services staff, and child development clinic staff could also participate. Through their participation in regional special education programs, many school divisions already have a similar structure in place that could be expanded upon.

Ohio Regional Training Teams

The Ohio Center for Autism and Low Incidence disabilities (OCALI) provides support to regional training teams. These teams, whose services include recommending specific interventions that schools should use to serve individual students, have a regional liaison with OCALI.

Developing Appropriate Goals/Objectives and Tracking Progress

As the federal government and other stakeholders continue to emphasize the importance of data in educational programming, schools will come under increasing pressure to provide concrete evidence of the impact of their educational programming. In response, the State could explore several options to improve the ability of school personnel to develop goals and objectives that appropriately account for the core deficits of students with ASDs. In addition, steps could also be taken to ensure that school staff have the skills to measure student progress toward appropriate goals and objectives and use these data to make programming decisions. Some advantages and disadvantages of these options are shown in Table 26.

Table 26: Advantages and Disadvantages of Options to Develop Goals/Objectives and Monitor Progress

Options	Advantages	Disadvantages
Enhance Ability to Develop Goals and Objectives		
Create model IEP	Provides guidance on effective educational programming for ASDs Provides training tool for schools	Difficult to balance with emphasis on individualization
Train teachers on IEP development	Incorporated into existing training activities	Follow-up would be resource intensive
Review ASD IEPs	Increases accountability	Requires training of "reviewers"
Include ASD expert on IEP team	Ensures that IEP development is informed by someone knowledgeable in ASDs	Creates additional staff time commitments May suggest a one size fits all approach Could devalue the input of other IEP team members
Enhance Ability to Track Student Progress		
Train teachers on measuring progress	Increases uniformity	None
Create progress monitoring pilot	Can be expanded if successful Uses lessons learned from another state	None

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

IEPs Differentiated for Students with ASDs in Illinois and Washington

State law in Illinois and Washington requires schools to use IEPs to address the unique needs of students with ASDs, including communication and social skills interventions.

Enhance Ability of School Personnel to Develop Appropriate Goals and Objectives. To demonstrate how schools can develop IEPs that include measurable goals addressing the core deficits of students with ASDs, the State should develop a model IEP that addresses the key domains of these students' functioning, including behavior, communication, sensory, and cognitive skills. The model IEP could include a template for writing and measuring goals and objectives that are aligned with these domains. The IEP could also reserve a space for detailing how the student's educational program will address the development of social skills and life skills, as well how generalization will be addressed in the curriculum. The State could also develop a checklist of essential items that must be reflected in the IEP and require schools to use this checklist in developing educational plans. DOE could revise its special education regulations to require schools to use the model IEP format, or this model IEP could be recommended for use by the ASD service guidelines currently being developed by the department. To reinforce the purpose of the model IEP and ensure that school personnel know how to use it, DOE could provide statewide training. To promote accountability and identify areas that require additional technical assistance, DOE could review samples of IEPs for students with ASDs.

Recommendation (9). The Department of Education should develop a model individualized education program (IEP) for Virginia students with autism spectrum disorders. The model IEP should include guidance on (1) developing appropriate and measurable goals and objectives; (2) addressing all major domains of functioning for students with autism spectrum disorders, including behavior, communication, sensory, and cognitive skills; (3) building social and life skills; and (4) fostering generalization of skills to environments other than the school.

Finally, DOE could amend its special education regulations to require that IEP teams for students with ASDs be composed of professionals who are knowledgeable about the core deficits of ASDs, the identification of research-based interventions that are best matched to their needs, and the application of these interventions. DOE could alternatively include this recommendation in its ASD service guidelines. The division-level ASD expert described previously or a special education teacher who has earned the ASD certificate could serve on the IEP team to meet this requirement.

Enhance School Capacity to Track Student Progress. To assist schools with capturing data that supports the goals established for students with ASDs, the State could begin by training school personnel. This training could be made available either online through the VAC, or during workshops. According to DOE staff, more intensive, small group training would be most effective for developing this skill. However, training will not provide teachers with a mechanism to collect data.

Pennsylvania Progress Monitoring

Pennsylvania's Training and Technical Assistance Network has initiated a "progress monitoring" project that involves collecting and analyzing data to measure student progress toward goals and objectives. By measuring students' progress over short time periods (for example, weekly to monthly), professionals are able to "compare the student's expected and actual rates of learning" and make necessary adjustments to the student's services.

To supply teachers with the tools needed to monitor student progress, the State could follow Pennsylvania's approach on a pilot basis. To implement this option would require identifying a data collection tool, supplying an information system tool to record data, training school staff on data collection and analysis, and providing ongoing technical assistance. According to Pennsylvania teachers who participated in the pilot, the time required to collect data was worthwhile because it rendered instructional time more effective over time. In addition, this approach would supply concrete evidence that can be used by teachers to adjust educational programming, and also ensure that all parties (including school staff, parents, and students) know what is expected and whether expectations are met.

Transition to Adulthood Could Be Improved Through Planning and Services

While the State has undertaken efforts to improve the ability of school personnel to develop appropriate transition plans for special education students, these efforts could more specifically focus on the potentially unique needs of students with ASDs. Further, students with ASDs could be granted more opportunities to develop social, life, and vocational skills needed to reach a greater degree of independence. The following options address both the competencies of school staff and the availability of programming to ensure that effective transition planning occurs for students with ASDs. Table 27 presents the major advantages and disadvantages of these options.

Clearly Establish Expectations for Transition Planning for Students With ASDs. DOE could continue to collect outcome data for students with ASDs. DOE currently reports specific data on transition planning and outcomes to the federal government, including data on schools' development of transition IEPs. Information is available on the development of transition IEPs for students with ASDs. DOE could require schools to over sample IEPs of students with ASDs to provide information on schools' ability to address the unique transition needs of these students as compared to students with other disabilities. Virginia also reports data on the transition outcomes of students one year after they exit school. DOE is able to analyze these survey responses by disability, and so it could focus on the transition outcomes of this subset of students to identify potential gaps in schools' abilities to prepare students with ASDs for independence.

Table 27: Advantages and Disadvantages of Options to Improve Transition Services

Options	Advantages	Disadvantages
Establish Expectations for Transition Planning		
Analyze transition indicators for students with ASDs	Builds on existing efforts Allows comparison of ASDs to other disabilities	Need to over sample for ASDs
Develop transition guidelines	Creates common language for stakeholders Identifies States priorities	Requires staff time and resources If too prescriptive, may not be consistent with emphasis on individualization May devalue local best practices
Increase Staff Support and Resources		
Build capacity through regional consortia	Identifies and develops community resources Planning focuses on transition	May be overshadowed by other issues if not made a required member
Create regional or division-level position for transition	Improves transition planning Ensures focus on transition plans Creates school-community liaison Enhances strategic planning Builds upon existing infrastructure	Requires additional staff training
Expand Vocational Training Programs		
Expand capacity of WWRC's high school transition program	Builds on successful program Builds WWRC expertise in ASDs	May only be appropriate for higher functioning students Demands greater staff and other program resources
Enhance vocational rehabilitation centers	Improves access to vocational training	May require student travel

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

To provide a resource for schools, parents, and students, to use in developing transition plans for special education students, DOE could develop a manual of transition guidelines. Through these guidelines, DOE should emphasize the need to account for the complex needs of students with ASDs. DOE could use the guidelines to emphasize the importance of incorporating life skills training into the high school curriculum. Without life skills, students will exit school unprepared for employment or further education. JLARC staff have identified guidelines published by Virginia experts that suggest a framework for providing transition services to students with ASDs. These are *Autism and the Transition to Adulthood* (2009) and *A Guide for Transition to Adulthood* (2006). The first provides examples of transition IEPs that capture the unique transition needs of students with ASDs, including social and life skills. In addition, Commonwealth Autism Service has recently developed a comprehensive transition "helpbook" for families, which could be used to incorporate the issues of particular interest to families.

Ohio Transition Guidelines

The Ohio Center for Autism and Low Incidence Disabilities developed transition guidelines for students with ASDs. The manual addresses IEP requirements for transition, age appropriate transition assessments, the recommended content of school programming, employment and postsecondary education issues, and supported living. The manual focuses on transition strategies to address ASD-specific impairments, such as organizational skills, repetitive behavior, and social skills.

Recommendation (10). The Department of Education should create transition guidelines that offer strategies for (1) addressing the unique and complex needs of high school students with autism spectrum disorders; (2) securing the services needed to build life, social, and vocational skills; and (3) positioning them for pursuing opportunities of their choice after these students exit the school system.

Increase Staff Support and Resources for Transition Services. School personnel could be required to play a more active role in improving the continuity of services between school and post-school. Specifically, the regional ASD consortia described above could explore opportunities to provide community-based life skills and job-readiness training for students through area employers, in conjunction with DRS.

To ensure that special education teachers have access to someone with transition-specific expertise, the State could create full-time division-level positions to focus on transition services, including developing partnerships with area employers and other community providers to improve the availability of opportunities for special education students to gain life, vocational, and job-readiness skills. Individuals in these positions would need to be trained on the unique transition needs of students in all disability categories, including ASDs, and could be mandated members of the regional ASD consortia described above. The staff in these positions could identify gaps in transition-related services and develop strategies for ensuring that students with ASDs attain their full potential for independence. To account for differences in the size of school divisions, the number of transition specialists could be based on the number of special education students in the division.

Woodrow Wilson Rehabilitation Center

Through the Post-secondary Education Rehabilitation Transition (PERT) program, the WWRC provides life skills and vocational training to high school youth with disabilities to prepare them for employment. This program is available to all schools, but there are not enough PERT slots to meet demand. In 2006, WWRC created a transition program specifically for youth with ASDs – the Individuals with Autism Exploring Life Options program. While WWRC staff described this program as successful, it was discontinued due to the resources required to serve youth with ASDs.

Expand Vocational Programs. The State could consider granting additional resources to Woodrow Wilson Rehabilitation Center (WWRC) to expand the PERT program to greater numbers of individuals with ASDs. The PERT program has been identified by State and school personnel as an excellent resource for special education students to develop vocational and life skills while they are still in school. Moreover, WWRC has recently begun to expand the capabilities of its staff to effectively serve students with ASDs. However, resource constraints prevent WWRC from serving all students who could benefit from the program.

The legislature could also consider providing funding for school divisions to revive regional vocational rehabilitation centers that would offer job and life skills training in both a classroom and community-based setting. In the past, school divisions have used State and local funds to create regional vocational rehabilitation centers to equip special education students with these skills. However, these efforts are voluntary on the part of schools and have reportedly diminished as schools have taken on other priorities. For those still operating, services offered vary and may not include the types of prevocational skills required by many students with ASDs. Increasing the availability of these centers and ensuring that they provide prevocational training to students who could benefit from it would improve the schools' ability to foster the skills needed for future employment and independent living.

Additional Options to Improve Services for School-Age Virginians With ASDs

The State could also consider options for service provision to students with ASDs apart from School Part B funded services. The avenues through which school-age children could access these ASD-specific services are the same as those discussed in Chapter 6. Children with ASDs could access supplemental services through Medicaid or a regional office, or attend a private school of their parents' choice. These options are not mutually exclusive, and could also be implemented in combination with improvements made to school-based programs. Table 28 shows the various advantages and disadvantages associated with these options.

Supplement School Services With New and Existing Medicaid Waiver Services. As discussed in Chapter 6, Virginia could modify its existing waiver programs that benefit individuals with ASDs to provide ASD-specific interventions, such as applied behavioral analysis. In addition, more information could be shared with families to ensure that children with ASDs enroll in available programs, such as the Elderly or Disabled with Consumer Direction waiver, and access available services through the Early and Periodic Screening, Diagnosis, and Treatment program. The State could also consider implementing a new Medicaid waiver specifically for children with ASDs. A group of Virginia stakeholders is currently being assembled by the Department of Medical Assistance Services (DMAS) to explore this possibility and should complete its work by the fall of 2009. Chapter 6 includes examples of other states' efforts to implement ASD-specific Medicaid waivers.

Deliver ASD Services Through Regional Offices. Regional offices described in Chapter 6 could also be used to provide services to school-age children with ASDs. Specifically, Virginia could consider expanding the capabilities of the 40 community services boards (CSBs) to provide direct services to school-age children with ASDs. The State could also consider using university-based regional centers to supplement the services provided by school personnel.

Table 28: Advantages and Disadvantages of Additional Options to Improve Virginia's Services for School-Age Children With ASDs

Options	Advantages	Disadvantages
Increase Family and Provider Knowledge		
Develop information packet about ASD services and available Medicaid resources	Improves understanding among families, case managers, providers	Increases demand for services
Develop service guidelines for serving individuals with ASDs	Ensures service planning process addresses ASD-related needs Not "policy" so allows for flexibility and individualization	Not "policy" so providers not required to follow
Require Medicaid providers to complete ASD training	Increases provider knowledge Increases ability to provide appropriate and meaningful services	Increases need for provider training Providers may not be willing to serve this population
Develop ASD Standards and Rates for Medicaid Providers		
Develop ASD provider category and standards	Creates ASD-specific provider standards and qualifications Assists families	Increases demand for services
Develop ASD provider rates	Better reflects provider qualifications, which could lower costs	None
Adjust Current Waiver Services		
Provide ASD therapies	Better address needs of clients with ASDs Increase waiver providers who specialize in ASD treatments	Increases demand for services Requires federal and State approval Does not benefit those on waiting list or who do not meet eligibility
Create New ASD Waiver		
Create waiver specifically for individuals with ASDs	Service package designed specifically for ASD Not competing with other disability populations Increases number of providers who specialize in ASD treatment	Requires federal approval Does not benefit those not eligible Creates potential for waiting list depending on number of slots Requires building provider capacity May be inconsistent with efforts to eliminate disability-specific programs May diminish resources available for existing waiver services
Provide ASD Services Through Regional Offices		
Use community services boards	Uses existing infrastructure CSBs house most Part C offices Available in 40 regional locations	CSBs focus on intellectual rather than other developmental disabilities Requires additional staffing and training
Use child development clinics	Uses existing infrastructure and expertise	Locations are limited to five statewide Requires significant additional staffing
Use university-based centers	Uses clinical expertise	No existing infrastructure
Provide Educational Alternatives		
Create ASD scholarship program	Increases parent/caregiver choices Participating children can access more specialized services Creates competition for public schools	Tuition amount may not cover all costs leading to inequity Private schools not held accountable to IDEA or NCLB standards Creates additional administrative responsibilities

Source: Staff analysis of research literature, other states' practices, and interviews with State agencies.

Implement an Autism Tuition Grant Program. The General Assembly could also reconsider legislation to implement the Virginia Autism Tuition Grant Program. Legislation introduced during the 2009 General Assembly session would have created a grant program allowing parents to use vouchers to send eligible children with ASDs to a nonsectarian private school, another public school within their district, or a public school in an adjacent division. Chapter 6 provides examples of other states that have implemented or considered similar voucher programs.

Summary of Options to Improve the Delivery of Services to School-Age Children With ASDs

In addition to having different policy merits, options described in this chapter vary in terms of the financial and human resources required, the extent to which they address the issues discussed in this chapter, and the time needed for implementation. Figure 21 summarizes these implementation considerations and reflects the best judgment of JLARC staff based on discussions with experts and knowledge gained during this review. To facilitate the State's decision regarding whether and how to improve the delivery of services to school-age Virginians with ASDs, the State departments of Education, Medical Assistance Services, and Behavioral Health and Developmental Services should collaborate with relevant stakeholders to weigh policy and implementation considerations, and identify which options are most suitable to reshape the programs administered by their agencies.

Recommendation (11). The Department of Education should collaborate with relevant stakeholders to (1) evaluate the options for improving the delivery of services to school-age children with autism spectrum disorders by increasing the consistency of service provision, enhancing its professional development programs, developing goals and objectives and monitoring progress, improving transition services, and offering educational alternatives through a scholarship program; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

Recommendation (12). The Department of Medical Assistance Services should collaborate with relevant stakeholders to (1) evaluate the options for improving the delivery of services to school-age children with autism spectrum disorders by increasing knowledge about Medicaid services, developing standards and rates for Medicaid providers, and adjusting existing or creating new waiver programs; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

Recommendation (13). The Department of Behavioral Health and Developmental Services should collaborate with relevant stakeholders to (1) evaluate the options for improving the delivery of services to school-age children with autism spectrum disorders by developing services through regional offices; and (2) identify no later than March 31, 2010, which, if any, options are most beneficial to pursue.

Figure 21: Implementation Considerations for Options to Improve the Delivery of Services to School-Age Virginians With ASDs

Major Goal	Resources Needed	Extent to Which Addresses Major Goal[a]	Time Needed to Implement
Provide Greater DOE Oversight to Implement Options			
Add DOE Staff	--	★★	🕒🕒
Provide Guidance on Research-Based Practices			
Develop ASD Best Practice Service Guidelines	--	★★★	🕒
Enhance Professional Development Programs			
Improve Access to In-Service Training	↓	★★	🕒
Increase Professional Qualifications of Teachers			
Require new special education teachers to attend ASD awareness training		★	🕒🕒
Require/provide incentives for newly hired special education teachers to complete ASD coursework/certification		★★	🕒🕒
Provide incentives for current school staff to complete ASD coursework		★★	🕒🕒
Require/provide incentives for newly hired general education teachers to complete ASD coursework		★★	🕒🕒
Require minimum number of teachers per division with ASD certification		★★★	🕒🕒🕒
Improve Access to ASD Experts			
Identify model schools		★★	🕒🕒🕒
Expand train-the-trainer approach statewide		★★	🕒🕒
Enhance T/TAC expertise and ability to provide hands-on training		★★★	🕒🕒
Create school division-level ASD experts		★★★	🕒
Identify and Prioritize Training Needs		★★★	🕒🕒
Develop Goals and Objectives and Track Progress			
Ehnance Ability of School Personnel to Develop Goals and Objectives			
Create model IEP for students with ASDs	↓	★★	🕒
Train teachers on IEP development for students with ASDs		★★	🕒🕒
Regularly review sample of ASD student IEPs		★	🕒🕒🕒
Include ASD expert on IEP team		★★★	🕒
Enhance Ability of School Personnel to Track Student Progress			
Train teachers on measuring ASD student progress	↓	★★	🕒🕒
Create progress monitoring pilot		★★	🕒🕒🕒
Improve Transition Services			
Establish Expectations for Transition Planning			
Report State Performance Plan transition indicators for students with ASDs	↓	★	🕒
Develop transition guidelines, differentiated for students with ASDs		★★★	🕒🕒🕒
Increase Staff Support and Resources		★★★	🕒🕒
Expand Vocational Training Programs			
Expand WWRC's PERT program for students with ASDs		★★	🕒
Enhance vocational rehabilitation centers for students with disabilities		★★	🕒🕒🕒
Expand Access to Services Through Medicaid or Other Options			
Increase Family and Provider Knowledge of Medicaid Services			
Develop Medicaid information packet	↓	★	🕒🕒
Develop Medicaid service guidelines for ASDs		★★	🕒🕒
Require ASD training of Medicaid providers		★★	🕒🕒🕒
Develop ASD Standards and Rates for Medicaid Providers	--	★★	🕒🕒🕒
Adjust current waiver services	--	★★★	🕒🕒🕒
Create new ASD-specific waiver	--	★★★	🕒🕒🕒
Provide ASD services through regional offices	--	★★	🕒🕒🕒
Create ASD scholarship program	--	★	🕒🕒

Least ↓ Most	★	Some Key Issues	🕒	< 6 Months
	★★	Many Key Issues	🕒🕒	6-18 Months
	★★★	Most Key Issues	🕒🕒🕒	> 18 Months

Note: --, Rating is not applicable because only one option is listed.

[a] Ratings reflect the extent to which each option addresses the major goal described in the gray-shaded row.

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

Chapter 8

Fostering Greater Independence Among Adults With Autism Spectrum Disorders

In Summary

Adults with ASDs are less likely to realize their potential for independent living than adults with other disabilities. To achieve and maintain a favorable quality of life, many adults with ASDs will require ongoing services and supports, but access to these is limited in Virginia. The State's system of employment services for individuals with disabilities is hampered by eligibility restrictions, a lack of vocational rehabilitation staff with training in ASDs, and waiting lists for services. Similarly, Virginia's Medicaid-supported employment and case management services are restricted by eligibility requirements, waiting lists, and a lack of qualified providers. However, Virginia has several options for expanding existing initiatives to broaden the array of available services. These options could improve the continuity of service provision across all life stages and help ensure that adults with ASDs are able to achieve their greatest possible degree of independence.

Due to the chronic nature of their condition, many individuals with autism spectrum disorders (ASDs) will require a variety of services and supports across all life stages. Individuals with ASDs will likely spend the majority of their lives as adults, yet few services and supports are available to them after the age of 21.

Two primary factors distinguish the availability of services for youths versus adults with ASDs. First, although the Individuals with Disabilities Education Act (IDEA) requires that states provide needed early intervention and special education services to eligible children with disabilities, there are no such entitlements for adults. Instead, federal and State programs that provide services and supports to adults with disabilities receive limited funding. Second, whereas Part C Early Intervention offices and schools provide case management for students, there is no case management system for most adults with ASDs.

Issues affecting adults with ASDs are still emerging across the country, and the process of addressing them is complicated by the lack of research-based practices for fostering independence. However, JLARC staff have identified several options that the State could consider for strengthening existing State programs, primarily through improved employment supports and expanded Medicaid waiver services.

Chapter Research Methods

JLARC staff interviewed a variety of stakeholders, including Department of Rehabilitative Services (DRS) central office staff, DRS field staff, personnel at several Centers for Independent Living, and staff at the Department of Medical Assistance Services. JLARC staff also administered a survey of individuals with ASDs and their caregivers and conducted a review of research literature and practices in other states. Additional details on study research methods can be found in Appendix B.

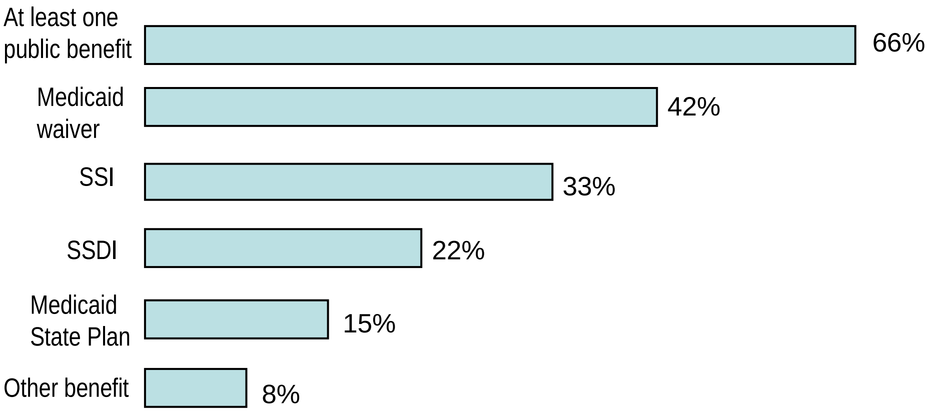
FEW ADULTS WITH ASDs HAVE ACHIEVED INDEPENDENCE

Results from a JLARC staff survey of individuals and their caregivers indicate that only seven percent of individuals with ASDs had achieved the greatest possible degree of independence, and only eight percent lived completely independently. Adults with ASDs who cannot achieve their potential for independence may rely on public programs, such as Medicaid and Social Security, which adds to government costs. Based on the JLARC staff survey of individuals with ASDs and their caregivers, respondents reported that two-thirds of adults are enrolled in at least one public benefit program, and approximately 42 percent are enrolled in two or more public programs (Figure 22). Moreover, 42 percent are enrolled in a Medicaid waiver program, one-third reportedly rely on Supplemental Security Income (SSI), and 22 percent rely on Social Security Disability Insurance (SSDI).

SSI and SSDI

SSI is a means-tested federal benefit available to low income and disabled or aged individuals. In 2009, SSI benefits could amount to $674 per month. SSDI is a federal benefit available to individuals whose disability prevents them from continuing to work. SSDI payments are based on the amount of payroll taxes paid to the federal government while the individual was working, and can total up to approximately $1,600 per month.

Figure 22: Majority of Adults With ASDs Responding to a JLARC Staff Survey Rely on at Least One Public Program



Note: Other public programs include General Relief, Food Stamps, Temporary Assistance for Needy Families, and public housing assistance.

Source: JLARC staff survey of individuals with ASDs and their caregivers.

EMPLOYMENT IS KEY TO INDEPENDENCE, BUT SYSTEM LACKS CAPACITY TO PROVIDE ASD-SPECIFIC SUPPORTS

Due to the complex nature of ASDs, adults on the autism spectrum face unique barriers to gainful employment, which Virginia's current system cannot fully accommodate. While employment is not a realistic goal for some of these adults, others possess valuable abilities but require varying levels of therapy and support in order to obtain and maintain a job. In general, these supports include strategies to help them identify appropriate employment options and function well in a typical work environment and a system that provides long-term supported employment services. In the JLARC staff survey of individuals with ASDs and their caregivers, employment supports were the most frequently cited services needed in order for adults to achieve their highest possible degree of independence and well-being.

Adults With ASDs Tend to Experience Worse Employment Outcomes Than Individuals With Other Disabilities

Employment Categories

Competitive employment is a job in an integrated setting where an individual is paid minimum wage or more, but not less than customary wage and benefits paid for like work to non-disabled individuals.

Supported employment is competitive employment in an integrated setting with ongoing support services to help individuals with most significant disabilities maintain this employment.

Sheltered workshop employment is provided by organizations that offer employment opportunities to people with disabilities in a non-integrated environment.

Persons with ASDs are among the least likely to be engaged in paid employment compared to individuals with other disabilities. A longitudinal study conducted for the U.S. DOE found that individuals with ASDs were less likely to be working toward competitive employment than individuals with other types of disabilities, including intellectual disabilities and emotional disturbances, prior to graduating high school. Instead, individuals with ASDs were more likely to have supported or sheltered employment as post-secondary employment goals. This same study found that two years after completing high school, adults with ASDs were less likely to be employed (27.6 percent) than adults with other types of disabilities (57.2 percent). Similarly, results from a JLARC staff survey of individuals with ASDs and their caregivers indicate that many Virginians with ASDs are not reaching their employment potential, even though employment was identified as a realistic goal for 85 percent of adults in the survey. The respondents indicated that adults with ASDs may be underemployed with only (1) one-quarter relying on income from a job, (2) one-third employed, with the majority working less than full-time, and (3) fewer than one-third fully utilizing their skills in their employment setting.

Research has found that adults with ASDs often have difficulty securing and maintaining paid employment due to impaired communication and social skills, such as being inattentive to co-workers; having difficulty establishing relationships with co-workers; and being unable to use or interpret social cues through facial expressions or body language. This was confirmed by Department of Rehabilitation Services (DRS) field staff and other vocational rehabilitation experts in the State. Further, 43 percent of adults and caregivers responding to the JLARC staff survey identified social skills training as a service that is most important for achieving the highest possible degree of independence. Stakeholders provided JLARC staff with multiple examples of individuals with Asperger's syndrome who were highly intelligent and capable employees, but whose ability to maintain a job was compromised by their limited ability to function appropriately in an integrated work setting. These challenges do not mean that employment is not a realistic goal for individuals with ASDs, but rather that intensive job preparation training and long-term on-the-job support may be needed to facilitate employment.

Department of Rehabilitative Services Is Not Structured to Provide Employment Supports Needed by Virginians With ASDs

DRS Field Office Focus on ASDs

The Fairfax County DRS field office has begun to improve its ASD service capacity in response to recent service demands. Staff have observed that job coaches would be the ideal providers of social and life skills instruction for individuals with ASDs, but they are insufficiently trained to do so. In response, staff are developing an in-house training course on this topic.

DRS, which is responsible for providing vocational rehabilitation services to Virginians with disabilities, appears unable to consistently provide the types and intensity of services and supports required for many individuals with ASDs to be successfully employed. Many respondents to the JLARC staff survey of caregivers and individuals with ASDs expressed dissatisfaction with DRS services. Of the 43 percent who reported having used DRS services, most found services to be inadequate in helping them acquire job skills (58 percent) or look for a job (53 percent). Almost half found DRS services to be inadequate in obtaining a job (41 percent) or keeping a job (42 percent). These results appear attributable, at least in part, to eligibility criteria that some adults with ASDs do not meet, inadequate DRS staff training, resource constraints, and lack of employer interest in hiring individuals with ASDs. Yet, DRS data show that investing vocational rehabilitation resources in clients with ASDs may be cost effective. Despite the fact that these clients took two months longer (on average) to serve in FY 2008, 65 percent were able to maintain employment for 90 days compared to 56 percent of all DRS clients.

Adults With ASDs May Not Consistently Be Eligible for DRS Services. According to DRS staff, some individuals with ASDs may not be eligible for vocational rehabilitation services because their disabling condition is too severe to allow them to benefit from these services. For example, some individuals with ASDs require services and supports to help them develop basic social and communication skills before they can be considered employable, which is a prerequisite of receiving DRS employment services. According to staff at the Woodrow Wilson Rehabilitation Center (WWRC), a State-owned and operated rehabilitation center, residents with ASDs tend to be less ready to function in a work environment than other residents and typically need help developing problem-solving and social skills first. However, working with clients with ASDs is a resource-intensive undertaking. According to DRS staff, the vocational rehabilitation system is a “work program” and is “not there to provide social skills” or other services that could help individuals with ASDs who have the most severe disabilities develop the social and communication skills that would make them employable. Still, DRS central office staff stated that eligibility determinations are based on a field office counselor’s assessment of employability, which can be subjective. Consequently, whether and which individuals with ASDs are found eligible for DRS services varies across the State.

According to DRS staff, the vocational rehabilitation system is a "work program" and is "not there to provide social skills" or other services that could help individuals with ASDs who have the most severe disabilities develop the social and communication skills that would make them employable.

DRS Services Are Time-Limited. The vocational rehabilitation program’s cap on the duration of services for eligible clients is another factor that limits its utility for some individuals with ASDs. Once a DRS client is in a stable job placement, DRS will provide job coaching services for at least 90 days before the case is closed. However, individuals with ASDs often require periodic, ongoing job coaching services in order to maintain employment. For example, individuals on the autism spectrum may be unable to adjust to changes in work environment that may occur through turn-over among co-workers or supervisors. The availability of job coaching supports is critical to the individual's ability to manage these work environment transitions and maintain employment. In fact, nearly half of the respondents to the JLARC staff survey of individuals with ASDs and their caregivers indicated that increased opportunities for supported employment was a critical service needed to achieve greater independence.

In 1995, the Virginia General Assembly created 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. This program is funded exclusively with general funds and has the potential to ensure that individuals with ASDs who need ongoing support remain successfully employed. According to DRS, 96 adults with ASDs received LTESS supports in FY 2008, representing three percent of all LTESS recipients. Because funding for the program is capped, not all individuals who require long-term supports are able to receive them, but data are not available to determine the extent of unmet needs. In FY 2008, LTESS funding was $5.3 million or seven percent of total vocational rehabilitation funding. The 2009 State budget reduced LTESS funding by nearly 30 percent, or $1.5 million, for the 2009-2010 biennium. While funding shifted from other programs is intended to compensate for a portion of these reductions, it is likely that fewer individuals will receive needed long-term employment supports.

DRS Staff Need Access to ASD Training Opportunities. Even if more individuals with ASDs were eligible for DRS services, DRS staff have indicated that their case managers and job coaches may not be sufficiently trained to meet the unique needs of these individuals. Field office staff have reportedly expressed an interest in ASD-specific training opportunities. In its 2009 strategic plan, DRS described plans to provide ASD-specific training to its field office staff by partnering with the VCU Rehabilitation Research and Treatment Center. The extent to which the staff employed by the 82 employment services organizations (ESOs) that contract with DRS for direct service provision are trained in ASD-specific service delivery is unknown.

Evidence suggests that staff training could improve the rehabilitation rate of clients with ASDs. In 2007, the WWRC partnered with

Commonwealth Autism Service to undertake an extensive staff development effort related to ASDs. WWRC staff reported having enhanced their ability to improve the life and vocational skills of these clients. In fact, for DRS clients served between 2005 and 2009, the rehabilitation rate for WWRC participants with ASDs was 6.7 percentage points higher than for clients with ASDs who did not participate in a WWRC program.

Impact of Federal Stimulus Funding

Due to additional resources from the 2009 American Recovery and Reinvestment Act, DRS began accepting new clients on May 1, 2009. However, services are only available to new clients who qualify under the priority category of "most significantly disabled."

DRS Lacks Resources to Meet Current Demand. Due to insufficient resources, from November 2008 to May 1, 2009, DRS did not accept any new cases under its federally mandated "order of selection" policy. As of March 2009, DRS was maintaining a waiting list of 2,405 individuals, 394 (16 percent) of whom had an ASD diagnosis. In addition, the 2009 budget passed by the Governor and General Assembly will reduce the amount of general funds for vocational rehabilitation services by $1.2 million. The fact that DRS was not taking new cases was cited as a significant or moderate challenge to effective transition planning by 44 percent of schools that responded to a JLARC staff survey. Even though additional resources in the form of federal stimulus funds are being used to open an order of selection category ("most significantly disabled"), DRS will remain under a federally mandated order of selection. While many individuals with ASDs may qualify under the order of selection based on the severity of their disability, individuals with lesser degrees of impairment, but often greater marketable abilities (such as persons with Asperger's syndrome), may be placed on the waiting list for services.

Order of Selection

When limited resources prevent DRS from serving all eligible vocational rehabilitation clients, the federal government requires that services be provided based on priority categories. Federal law and State regulations require that individuals with the most severe disabilities be served first. DRS opens and closes the four priority categories based on available resources.

Insufficient Number of Employers Available to Hire Individuals With ASDs. In addition to inadequate services and supports to foster greater employment among adults with ASDs, there also appears to be a lack of employers in Virginia who are able or willing to hire employees with these disabilities. Twenty-nine percent of caregivers and individuals with ASDs responding to a staff survey reported that one of the primary barriers to independence and productivity was the insufficient number of employers who are willing to hire persons with ASDs. Due to the complex and unique nature of ASDs, these individuals are more likely to gain and maintain employment in a job setting that is customized according to their needs and abilities. This likely requires employer flexibility.

Employment Supports Are Covered by Medicaid Waivers, but Are Not Widely Used or Available

While Medicaid waivers offer critical employment supports and preparation to adults with ASDs, only those with severe functional impairments are eligible, and few of them appear to use these services. Based on the JLARC staff survey of individuals with ASDs and their caregivers, 42 percent of adults were receiving Medicaid waiver services. As described in Chapter 3, Virginia's two comprehensive waivers for people with developmental disabilities are the mental retardation (MR) waiver for those who have a co-occurring intellectual disability (ID), and the Individuals and Families with Developmental Disabilities Services (DD) waiver for those without an ID diagnosis. However, individuals with ASDs must be at risk of institutionalization to be eligible. While there are waiting lists for both waivers, persons with ASDs who were placed on the list as children should usually be fully enrolled by the time they reach adulthood. Individuals must currently wait an average of 2.7 years before obtaining an MR waiver slot and 4.8 years for a DD waiver slot. However, it is unclear how early families of children with ASDs typically apply for waiver services and the average wait time for a slot may continue to increase. The 2009 General Assembly enacted legislation requiring the Governor and the legislature to create a plan to eliminate waiting lists for both waivers within ten years.

Adults who are enrolled in either the DD or MR waiver can receive supported employment. Importantly, these waivers will also pay for providing prevocational training. Employment services and prevocational training can be received for up to 780 hours per year, or the equivalent to 98 eight-hour work days. However, Department of Medical Assistance Services (DMAS) data indicate that in FY 2008, only nine individuals on the DD waiver received supported employment and five received prevocational training, and fewer than ten percent of MR waiver recipients received supported employment services (579 individuals) and prevocational services (712 individuals). These relatively low numbers may reflect the fact that waiver recipients must meet functional criteria that place them at risk of institutionalization, making employment an unrealistic option for them.

It should be noted that Virginia regulations require that waiver-funded prevocational or supported employment services be provided by vendors of DRS services or vendors that are certified by the Commission on Accreditation of Rehabilitation Facilities. To the extent that DRS vendors lack the expertise to provide supported employment services that are tailored to the unique needs of individuals with ASDs, this will also be true of waiver services.

COMMUNITY SUPPORTS ARE KEY TO INDEPENDENCE, BUT ARE LACKING ACROSS ALL DEVELOPMENTAL DISABILITIES

While employment supports are critical to the ability of adults with ASDs to engage in society as productive individuals, other supports may be needed to facilitate their highest possible degree of independence. Survey results indicate that additional housing, transportation, and community-based supports are needed for adults with ASDs. While some public programs exist to offer needed supports to adults with ASDs, they currently are not meeting the demand. The long-term outlook can be uncertain for adults with ASDs, especially those who do not receive waiver services. Caregivers consistently expressed that their greatest concern was not knowing who would care for their child once they no longer could.

Olmstead v. L. C.

This 1999 U.S. Supreme Court decision required states to develop plans to integrate individuals with disabilities into mainstream society to the fullest extent possible.

A lack of community supports can present challenges for all disabled Virginians who require certain accommodations or supports to maintain a favorable quality of life. As part of the State's Olmstead Initiative, several State agencies are collaborating in the development of solutions to bridge service gaps for Virginians with disabilities. Because the supports generally needed by individuals with disabilities are common across conditions, this effort has promise for addressing service gaps for adults on the autism spectrum as well.

Waiver Programs Do Not Guarantee Access to Needed Supports for Adults With ASDs

The DD and MR waivers represent the greatest opportunity for adults with ASDs to receive comprehensive, community-based services and supports. In particular, waiver recipients have access to day support, in-home, personal care, and transportation services that can help individuals with ASDs remain in their homes and communities. However, the DD waiver does not include congregate care provided in community-based settings, such as group homes. As a result, individuals with ASDs may be institutionalized once their caregiver is no longer able to support them because they lack the option to transition to a less restrictive, and less expensive, housing alternative. However, excluding congregate care from the DD waiver has contained program costs, which may have enabled more individuals to enroll. Due to the functional limitations required for waiver eligibility, an unknown number of individuals who could benefit from these types of supports will not have access to them because they do not meet eligibility criteria. Lastly, becoming a waiver recipient does not guarantee access to needed services. Families report difficulties locating waiver service providers who are willing or able to serve individuals with ASDs, either due to a lack of expertise or to inadequate reimbursement rates.

Centers for Independent Living Have Limited Capacity

Virginia's 16 Centers for Independent Living (CILs) are another public source of services and supports for adults with ASDs, but they do not appear to be commonly utilized by persons with ASDs. In FY 2008, CILs reported that 453 of their clients had an ASD diagnosis, which represented approximately five percent of all their clients. All CILs provide a limited array of core services, which include peer counseling, independent living skills training, information and referral, and advocacy, and a few also provide case management services through the DD waiver. While CILs rarely provide direct employment supports for clients, staff from at least one CIL reported that they have initiated these services to compensate for DRS's inability to meet service demands. Interviews with CIL staff indicate that CILs have not made a substantial effort to specifically address the service needs of individuals with ASDs.

OPTIONS TO FOSTER GREATER INDEPENDENCE AMONG ADULTS WITH ASDs

To ensure that Virginia has a system of care in place for adults with ASDs, the State could consider the options below. The absence of a strong system of service delivery and supports for adults with ASDs in Virginia was identified by all stakeholders as an area that the State should prioritize in its development of further ASD-specific policies. While investing greater resources in services for young children with ASDs could result in a comparatively lower demand for services in later life stages, the nature of ASDs is such that they will require ongoing, if intermittent, support throughout their lives. Moreover, the benefits of early intervention will not accrue to individuals with ASDs who are now preparing to transition out of school or already living as adults. The options presented in this section vary in terms of the resources and time needed for implementation as well as their impact on the issues described in this chapter.

Options to Foster Independence Through Improved Employment Services

JLARC staff have identified several options to improve the quality and availability of employment support services for adults with ASDs. To implement these options, ASD-specific training would need to be made available to State and local agency staff responsible for developing employment services plans for adults with ASDs, as well as staff of the employment services organizations (ESOs) who are largely responsible for direct service delivery. Further, improving the capacity of service providers to meet service demands would require additional funding to pay for employment supports. Table 29 lists various advantages and disadvantages associated with these options.

Table 29: Advantages and Disadvantages of Options to Foster Independence Through Enhanced Employment Services and Supports

Option	Advantages	Disadvantages
Train DRS and ESO staff on ASD skills competencies	Develops consistent knowledge across multiple provider types Improves DRS staff and ESOs' knowledge and abilities Coordinates with other trainings on skills competencies	Requires time for attending training
Use employer networks to encourage hiring of individuals with ASDs	Increases availability of employers for adults with ASDs Creates resource for vocational rehabilitation case managers and schools	Tax incentives may not be effective Does not guarantee that employers will hire challenging employees
Expand Long Term Employment Support Services Program	Addresses long-term job support needs of individuals with ASDs	Does not address gaps in ASD expertise for DRS and ESO staff
Provide basic social and communication skills training through CSBs and CILs	Builds upon existing infrastructure Expands availability of providers for social and communication skills training	Requires staff training on ASDs
Implement ASD-specific programming at DRS	Improves likelihood that individuals with ASDs will become eligible for DRS services Improves rehabilitation rate of clients with ASDs Addresses one of primary barriers to employment Could be used by schools as part of transition programming	DRS views as inconsistent with mission
Reduce or eliminate DRS waiting lists	Improves access to vocational rehabilitation services	Does not address gaps in ASD expertise for DRS and ESO staff

Source: Staff analysis of research literature, other states' practices, and interviews with State agencies.

Train DRS and Employment Services Organization Staff on Skills Competencies. To better educate field staff about the unique needs of individuals with ASDs, DRS could use the Virginia Autism Council's (VAC) "Skills Competencies for Professionals and Paraprofessionals in Virginia Supporting Individuals with Autism Across the Lifespan" ("skills competencies"). As described in Chapter 7, the skills competencies are a professional development tool for all types of service providers. DRS could assess the knowledge of its vocational rehabilitation and ESO staff against these competencies, which would provide DRS with a baseline understanding of the ability of its staff to effectively meet the needs of this population. Using that information, DRS could work with the VAC to develop or refine existing training materials for its field staff.

Virginia Business Leadership Network

The VABLN is an association of Virginia businesses that aims to improve businesses' ability to hire employees with disabilities.

Use Existing Employer Networks to Encourage Employers to Hire Employees with ASDs. To increase the pool of employers who are willing and able to hire persons with ASDs, DRS could also consider developing a consortium of businesses interested in hiring individuals with ASDs. The Virginia Business Leadership Network (VABLN) has already been formed to provide employers with training and support to successfully hire individuals with disabilities and could serve as a foundation for this consortium. This consortium could be used by case managers, such as DRS field staff, to identify potential employers for clients with ASDs.

DRS field offices statewide hold monthly networking meetings with employers. DRS could use the VABLN or the employer network meetings to orchestrate training for employers on hiring and accommodating employees with ASDs. As an incentive for more employers to hire individuals with ASDs, the General Assembly could also provide tax credits to members of this consortium that hire these individuals.

The General Assembly could also direct DRS to work with this group to develop further opportunities for both paid and unpaid employment for individuals with ASDs. A Delaware report on best practices for serving adults with ASDs emphasized the importance of a variety of options to help adults with ASDs become productive, which could include supported employment, volunteer opportunities, or more closely supervised sheltered employment.

Expand Long-Term Employment Support Services Program. Because individuals with ASDs are likely to require ongoing job-coaching or other employment supports, the General Assembly could expand the LTESS program. This program appears to be an important resource for ensuring that all adults with disabilities maintain competitive employment. However, the LTESS budget has been reduced by 30 percent for the FY 2009 and FY 2010 biennium. According to DRS staff, the ESOs that receive and manage the LTESS funds often rely on their own fundraising capabilities to supplement depleted LTESS funds. However, their ability to supplement DRS funding may decline due to the current unfavorable economic climate. If greater opportunities are made available for individuals with ASDs to develop the basic workplace skills needed to become ready for employment demand for LTESS supports will likely increase.

Community Services Boards and Centers for Independent Living Could Provide Social and Communication Skills Training. Some community services boards (CSBs) as well as CILs are equipped to provide the training on basic workplace skills needed by many adults with ASDs. The General Assembly could provide funding to build the capacity of CSBs and CILs to provide these basic life and job readiness skills, and DRS could contract with these agencies for this service. According to DMAS, the average annual per-person cost for prevocational services provided to Medicaid waiver recipients in FY 2008 was $4,481 for the DD waiver and $10,408 for the MR waiver.

ASD Supported Employment Pilot

In 2009, DRS, VCU, and the Faison School implemented a grant-funded pilot program for providing supported employment services to high school youth with ASDs. One hallmark of this program is an in-depth assessment of students' abilities that is performed at a job site over the course of several weeks. This situational assessment is longer than the typical assessment performed for other DRS clients, and is designed to specifically address the employment needs of students with ASDs.

DRS Could Implement an ASD-Specific Supported Employment Program. The General Assembly could also consider directing DRS to create an ASD-focused employment program and provide sufficient resources for the addition of staff and staff training, as well as the increased duration required for up-front assessment services. Rather than turn away individuals with ASDs who do not yet possess the social and communication skills required to function appropriately in a work environment, DRS could provide the training necessary to improve their employability. DRS could also provide more in-depth assessments of clients' needs at job sites. This would require staff training as well as additional central office and field office staff. DRS could also partner with the WWRC, CSBs, and CILs to provide these services.

DRS could also seek training support from other states that have implemented such programs, such as Connecticut and North Carolina. Due to the large numbers of individuals with ASDs who were being referred for vocational rehabilitation services, the Connecticut Bureau of Rehabilitation Services developed a "clinical committee model" to more specifically assess the needs and abilities of these potential clients. Through this model, the agency developed a multi-modal approach for providing prevocational skills to clients with ASDs, including direct teaching, finding opportunities for individuals to volunteer or obtain non-paid employment on a job site, working with families of clients to address basic skills like time management, and providing instruction about negotiating the physical layout of work spaces. These services are tailored specifically to adults on the autism spectrum and are supported through state and federal funds.

TEACCH Supported Employment Program

The North Carolina TEACCH program assists individuals with ASDs to find and maintain competitive employment. TEACCH has developed four different models of providing supported employment services, which are provided throughout the state by the TEACCH regional centers. Job coaches are specifically trained to work with adults with ASDs.

Reduce or Eliminate DRS Waiting Lists. The General Assembly could also consider appropriating funding to allow DRS to gradually eliminate the existing waiting list for services. This would help all individuals with disabilities who need employment supports to gain and maintain employment. This would also give schools another resource to improve transition planning for students with disabilities. A budget amendment introduced in the 2009 General Assembly Session sought to add $5 million to the 2009-2010 budget to open DRS services to those individuals who are considered the most significantly disabled, but was not adopted in the final budget.

Options to Foster Independence by Increasing the Availability of Comprehensive Medicaid Waiver Services

To enhance the availability of services and supports for individuals with ASDs who meet existing waiver criteria, the legislature could review the adequacy of reimbursement rates, offer training to build provider expertise, and add needed services through an existing or new waiver. In addition, waiver service providers could be further informed if the State were to offer service guidelines or require providers to receive ASD-specific training. Both options are discussed in greater detail in Chapter 6. Table 30 lists various advantages and disadvantages associated with these options.

The State could expand the array of services available to waiver recipients to meet more of their needs. In particular, congregate residential supports could become a covered service under the DD

Table 30: Advantages and Disadvantages of Options to Increase Availability of Comprehensive Medicaid Waiver Services

Option	Advantages	Disadvantages
Review adequacy of reimbursement rates	Determines whether reimbursement rates are adequate to maintain provider supply	Does not address provider expertise
Adopt service guidelines for serving individuals with ASDs	Ensures service planning process addresses ASD-related needs Not “policy,” so allows for flexibility and individualization	Not “policy,” so providers not required to follow
Require providers to complete ASD and early intervention training	Increases provider knowledge of ASDs Increases provider ability to provide appropriate and meaningful services	Requires increase in available trainings Providers may not be willing to serve this population
Add congregate care to DD waiver	Expands housing opportunities Reduces institutionalization	Requires federal approval
Create ASD waiver for adults only	Provides services tailored to specific needs of adults	Only one state has been approved for an ASD adults waiver No benefit for those who do not meet eligibility criteria Requires increasing provider capacity
Develop an ASD waiver for all ages	Simplifies application process for CMS, as opposed to one for adults and one for children Service package designed specifically for ASD Not competing with other disability populations Increases number of providers who specialize in ASD treatment	Creates additional administrative burdens Requires federal approval Does not benefit those not eligible Creates potential for waiting list depending on number of slots Requires building provider capacity May be inconsistent with efforts to eliminate disability-specific programs May diminish resources available for existing waiver services

Source: JLARC staff analysis of research literature, other states’ practices, and interviews with State agencies.

waiver. This service would enable adults with ASDs who can no longer remain in their home to transition into a supported, community-based environment that is both less expensive and less restrictive than institutional care. This option would also address one of the primary concerns expressed by caregivers regarding the future of their child once they can no longer care for them.

Based on the average annual cost of congregate care under the MR waiver in 2008, this service could cost approximately $66,000 per person. However, it is unknown how many DD waiver recipients would require this service, or for how long. To address the potential cost of adding congregate care as a covered service, DMAS could require family members caring for the individual in their home to demonstrate that they are no longer able to do so in order to qualify for this service.

The State could also consider creating an ASD-specific waiver strictly for adults, or for all ages, but with a portion of slots reserved for individuals over the age of 21. Services for this group could include those that have been identified as critical to independence, such as prevocational and vocational training, supported employment services, life skills, housing supports, respite services, and personal care services. Providing housing supports, such as group homes, would substantially increase the cost of the waiver, as described above. However, creating a new waiver may be inconsistent with current efforts in Virginia to eliminate the provision of services and supports through disability-specific programs.

Because there is already a shortage of Medicaid providers available to serve adults with ASDs, the State would have to undertake substantial efforts to improve provider capacity prior to the implementation of expanded waiver services. Pennsylvania is the only state that has been approved by the federal Centers for Medicare and Medicaid Services (CMS) for a Medicaid waiver for adults with ASDs. According to staff from Pennsylvania's Bureau of Autism Services, one of the primary challenges of implementing this waiver was the need to build a cadre of service providers trained in working with adults on the autism spectrum. The state assembled a team of ASD and behavioral professionals to develop training modules and provide training to direct service providers.

Other Options to Foster the Independence of Adults With Autism

JLARC staff also identified several State-funded options that could result in more comprehensive service delivery to adults with ASDs. Each of these options would allow the State to offer a broad range of services to adults with ASDs, and most can build upon or be modeled after existing initiatives and programs. These options are not mutually exclusive and can be implemented along with options

Table 31: Advantages and Disadvantages of Other Options to Foster Independence Among Adults with ASDs

Option	Advantages	Disadvantages
Focus Olmstead Implementation Team on ASDs	Coordinates efforts between Olmstead Implementation Team and the VAC	Requires additional staff time May be inconsistent with efforts to eliminate disability-specific policies
Provide case management for adults through CSBs	Have the staff expertise and structure to provide case management Are regional entities Department of Behavioral Health and Developmental Services is lead developmental disabilities agency	Have not historically provided services to persons with most types of developmental disabilities Requires additional staff training Youth transitioning out of school may be averse to yet another service provider
Provide case management for adults through DRS	DRS has case management program in place for other adults with multiple needs DRS case management providers are situated regionally	DRS/private case managers have limited ASD expertise Youth transitioning out of school may be averse to yet another service provider
Develop pilot program for comprehensive adult services	State has flexibility in eligibility guidelines Creates coordinated and comprehensive service delivery	Requires efforts to build provider qualifications Youth transitioning out of school may be averse to yet another service provider

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

discussed earlier in this section to expand both the array of services available to adults with ASDs and the number of individuals eligible to receive them. Table 31 lists various advantages and cons associated with these options.

Focus Olmstead Implementation Team on ASDs. To respond to the U.S. Supreme Court's ruling in *Olmstead v. L.C.* (1999), the General Assembly created an Olmstead Advisory Commission to focus on the State's progress toward integrating individuals with disabilities into the community versus institutions. A 2007 executive directive charged the Olmstead Community Integration Implementation Team to develop "Virginia's Cross Governmental Strategic Plan to Assure Continued Community Integration of Virginians with Disabilities" to report on progress toward the goal of community integration. This plan is updated annually, but does not focus specifically on the steps that could be taken to assure the integration of individuals with ASDs. While some services, like housing and transportation, may not need to be differentiated for this population, others such as employment supports or case management should be. Therefore, the General Assembly may wish to consider requiring the Olmstead Community Integration Implementation Team to include in its annual progress updates a discussion of the State's preparations for further integrating adults with ASDs into the community. This plan could specifically focus on the availability of supports like transportation, housing, employment services, health services, case management, and therapeutic supports needed to optimize the potential for these individuals to be fully integrated and productive members of society.

Recommendation (14). The General Assembly may wish to consider directing the Olmstead Community Integration Implementation Team to include in its action plan and implementation update a discussion of steps that can be taken to help Virginians with autism spectrum disorders achieve greater levels of independence and be further integrated in the community.

Case Management Could Be Provided to Adults. Rather than offer case management to all individuals with ASDs, as described in Chapter 4, this service could be offered specifically to adults. While children already often have access to a case manager (albeit with a limited focus) through the Early Intervention Part C office or School Part B programs, adults generally do not have a case manager who can link them to needed services available in the community, unless they are waiver recipients. Case management services could ensure that adults with ASDs are both aware of and able to access the services that are available to them. As described in Chapter 4, the State could create an ASD case management program that is administered by the CSBs, which are already staffed to provide case management services for their mental health and intellectually disabled clients.

Alternatively, the State could create a separate ASD case management program within DRS. DRS has already implemented a case management system for traumatic brain injury (TBI) survivors that could be used as a model for ASD case management. DRS staff provide case management services and can also contract with community-based providers for these services. In a 2007 JLARC report on TBI services, JLARC staff reported receiving many positive accounts of case management services provided through this program.

State Could Implement a Pilot Program for Adults With ASDs. To provide adults with ASDs with the supports needed to maximize independence, a comprehensive program could be launched on a pilot basis. Other states have funded such programs for adults with ASDs to address gaps in service availability. For example, Connecticut has developed a pilot program for adults with ASDs that provides case management, job coaching that focuses on developing basic skills needed to function in a work environment, and opportunities to obtain non-paid employment to improve their quality of life.

Pennsylvania has also developed a pilot program through its Bureau of Autism Services. The Pennsylvania Adult Community Autism Program (ACAP) was modeled after the state's Program for All Inclusive Care for the Elderly (PACE) program. Providers participating in the ACAP receive a capped amount of funding per client in exchange for assembling a network of professionals to comprehensively meet clients' needs. Virginia could implement a similar pilot program to provide case management and services that facilitate independent living, such as life skills training, to a limited number of adults with ASDs. This pilot program could be expanded in scope if it is deemed successful based on outcome measures developed by the State. Pennsylvania and Connecticut collect outcome data on the impact of their programs, which could serve as performance measurement examples for Virginia.

Summary of Options to Foster Greater Independence Among Adults With ASDs

In addition to having different policy merits, options described in this chapter vary in terms of the financial and human resources required, the extent to which they address the issues discussed in this chapter, and the time needed for implementation. Figure 23 summarizes these implementation considerations and reflects the best judgment of JLARC staff based on discussions with experts and knowledge gained during this review. To facilitate the State's decision regarding whether and how to foster greater independence among adults with ASDs, improve the delivery of services to school-age Virginians with ASDs, the State departments of Rehabilitative Services, Medical Assistance Services, and Behavioral Health and Developmental Services should collaborate with relevant stakeholders to weigh policy and implementation considerations, and identify which options are most suitable to reshape the programs administered by their agencies.

Recommendation (15). The Department of Rehabilitative Services should collaborate with relevant stakeholders to (1) evaluate the options for fostering greater independence among adults with autism spectrum disorders by improving employment services and supports; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

Recommendation (16). The Department of Medical Assistance Services should collaborate with relevant stakeholders to (1) evaluate the options for fostering greater independence among adults with autism spectrum disorders by improving Medicaid waiver programs; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

Recommendation (17). The Department of Behavioral Health and Developmental Services should collaborate with relevant stakeholders to (1) evaluate the options for fostering greater independence among adults with autism spectrum disorders; and (2) identify no later than March 31, 2010, which, if any, options are most beneficial to pursue.

Figure 23: Implementation Considerations for Options to Foster Greater Independence Among Adults With ASDs

Major Goals	Resources Needed	Extent to Which Addresses Major Goal[a]	Time Needed to Implement
Improve Employment Services and Supports			
Train DRS and ESO staff on ASD Skills Competencies	↓	★	🕒🕒
Use employer networks to encourage hiring of individuals with ASDs		★	🕒🕒
Expand Long-Term Employment Support Services Program		★	🕒
Provide basic social and communication skills training through CSBs/CILs		★★	🕒🕒🕒
Implement DRS programming on social and communication skills		★★	🕒🕒🕒
Reduce or eliminate DRS waiting lists		★★	🕒🕒
Expand Medicaid Waiver Services			
Add congregate care to the DD waiver	↓	★	🕒🕒
Review Medicaid provider rates		★	🕒🕒
Provide ASD training to Medicaid providers		★★	🕒🕒🕒
Create ASD waiver for adutls only		★	🕒🕒🕒
Other Options to Foster Greater Independence			
Focus Olmstead Implementation Team on ASDs	↓	★★	🕒🕒
Provide case management for adults		★★	🕒🕒🕒
Develop pilot program for comprehensive adult services		★★	🕒🕒🕒

Least ↓ Most

★	Some Key Issues	🕒	< 6 Months
★★	Many Key Issues	🕒🕒	6-18 Months
★★★	Most Key Issues	🕒🕒🕒	> 18 Months

[a] Ratings reflect the extent to which each option addresses the major goal described in the gray-shaded row.

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

Chapter

9

Enhancing Awareness of Autism Spectrum Disorders Among Virginia Public Safety Personnel

In Summary

Individuals with ASDs tend to encounter public safety personnel more frequently than the general population. They are more likely to be victimized or wander away from caregivers; exhibit behaviors that may appear suspicious to others; and are less likely to appreciate the seriousness of dangerous situations. Furthermore, some of the characteristics and behaviors exhibited by individuals with ASDs can complicate the work of public safety personnel. Public safety personnel who have some understanding of ASDs may be able to more effectively work with people with these disorders. However, few public safety personnel in Virginia have received such training. A variety of options could be explored to facilitate awareness of ASDs among public safety personnel.

Encounters involving public safety personnel can be especially stressful for individuals with ASDs, who often experience sensory problems with bright lights and loud noises. Furthermore, the social and communication deficits that are the hallmarks of ASDs make it difficult for individuals to advocate for themselves when confronted by law enforcement, rescue, or judicial personnel. Without adequate training, first responders may be unable to assist individuals with ASDs, and may in extreme cases cause harm. In addition, judicial personnel may pursue legal actions that do not account for the impact of ASDs on an individual's actions.

ASDs CAN COMPLICATE INTERACTIONS WITH PUBLIC SAFETY PERSONNEL

Individuals with ASDs tend to have more frequent and more dangerous encounters with public safety personnel. In many instances, individuals with ASDs react in unusual ways to unfamiliar stimuli such as a police car's flashing lights, a firefighter's protective gear, or an emergency medical technician's gurney, which can complicate already tense situations and in some cases, have severe ramifications. These unusual behaviors may be compounded by the person's inability to recognize social norms and communicate effectively, both characteristics of ASDs.

Public Safety Personnel Likely to Encounter Individuals With ASDs

Individuals with ASDs are more likely to interact with public safety personnel at some point in their lives than the general popu-

Chapter Research Methods

JLARC staff interviewed training staff in multiple State agencies, a nationally-recognized expert on ASD training for public safety, ASD training instructors in Virginia, and individuals involved in training efforts in other states. In addition, staff surveyed Virginia's 36 criminal justice academies, 75 percent of which responded. JLARC staff also conducted a review of the literature and training practices in other states. Additional details on study methods are available in Appendix B.

lation. According to a study conducted in the 1990s, individuals with developmental disabilities, which include ASDs, are seven times more likely than the general population to encounter law enforcement personnel. One of the main reasons for this increased likelihood is that individuals with disabilities are four to ten times more likely than the general population to be victimized. Characteristics typical of ASDs (such as being non-verbal, unable to effectively communicate, and naive regarding social situations) likely contribute to victimization. Individuals who are victimized may interact with a variety of public safety personnel, including law enforcement, emergency medical services (EMS), and judicial personnel.

Individuals with disabilities are four to ten times more likely than the general population to be victimized.

Individuals with ASDs may also be more likely to interact with law enforcement personnel because some of their unusual behaviors can be misinterpreted as suspicious or even criminal. For example, a person with an ASD may follow someone they find interesting with no criminal intent, but the person being followed may construe the behavior as stalking and contact law enforcement. In addition, a parent's attempts to de-escalate the behaviors of a child with an ASD may appear to be negligent or abusive and precipitate police involvement. For instance, a parent may need to restrain a child at risk of self-injury. The tendency of many individuals with ASDs to wander away from their homes and caregivers also increases their likelihood of encountering public safety personnel acting in a "search and rescue" capacity. Furthermore, some individuals with ASDs may be attracted to objects that could be dangerous, such as water or cars, or lack fear of the danger involved in certain situations.

Interactions Between Law Enforcement Officers and Persons With ASDs Can Have Adverse Consequences

Individuals with ASDs may have unusual reactions to a law officer's standard procedure and trigger responses that are not commensurate with the threat they truly pose. For example, a police car's siren may cause individuals with ASDs to either engage in self-stimulatory behavior (such as rocking back and forth) to calm themselves, or to react aggressively toward the officer. Individuals with ASDs may display other challenging behaviors, such as eye rolling, echolalia (echoing the words of others), responding affirmatively to all questions even when answers contradict each other, or fleeing the situation. These behaviors may prevent an officer from recognizing and reporting victimization, or cause them to misinterpret the behavior as defiance, non-compliance, or indicative of criminal intent.

Unlike other types of developmental disabilities, individuals with ASDs often have no obvious signs that would alert law officers to the possibility of a medical reason for these behaviors. As a result, the potential exists for encounters to result in serious injury or even death. Additionally, inappropriate encounters can also create liability issues for the law enforcement agencies involved. Although these types of incidents occur infrequently, they create substantial legal exposure for law enforcement agencies. Recent incidents in North Carolina and Tennessee illustrate how the lack of ASD awareness may have devastating consequences:

> ***Case Study***
>
> *In 2004, police officers from Statesville, North Carolina, responded to a call regarding a man with autism who was threatening his mother and a caregiver. The man was 45 years old and non-verbal. When the police arrived, they were informed that he had hit his mother. His caregiver had locked herself in the car, which he was circling. The officers had a physical altercation with the man, eventually restrained him, and placed him in the police car. The man's mother asked the police to take the man to the hospital, but they took him to the police station instead. At the police station, the man struggled against the personnel who tried to remove him from the car. The struggle ended in the man choking on his own vomit and dying of asphyxiation. A similar incident occurred in Knoxville, Tennessee, in 2000, when a man with an ASD died after a confrontation with law enforcement officers. This man's family later successfully sued the police department and social service agency, and was awarded $4.4 million.*

JLARC staff were unable to identify any recent incidents in Virginia involving law enforcement officers and persons with ASDs which resulted in serious injury or death. One incident involved a Virginia man with Asperger's syndrome who was "Tasered" by an officer at a mall, but the man did not appear to sustain any serious injuries. While the absence of known incidents in Virginia is encouraging, experts indicated that individuals with ASDs may have been harmed during an interaction with law enforcement, but did not disclose their disability.

Caregivers who responded to a staff survey also described several incidents between their child with an ASD and law enforcement officers working at their schools (including resource officers, security officers, and Drug Abuse Resistance Education officers). In most situations, the officer lacked an awareness and understanding of ASDs, which led to a misunderstanding of the child's behavior, and resulted in the child reportedly receiving undue punishments. The increasing number of students diagnosed with ASDs may result in more negative encounters with school-based officers.

Behaviors Displayed by People With ASDs Have the Potential to Complicate the Work of EMS, Fire, and Rescue Personnel

Attempts to help a person with an ASD in an emergency situation may be misinterpreted or trigger a behavior escalation. For example, persons with ASDs may interpret a rescue worker's efforts to lead them out of a burning building as threatening and respond by struggling. Additionally, individuals with ASDs may be hyper- or hypo-sensitive to pain and touch, which can complicate the efforts of emergency medical personnel in treating injuries or illnesses. For example, attempting to insert an intravenous (IV) line in a person with an ASD may elicit aggression or violence if the person is hypersensitive to touch or pain. Several respondents to the JLARC staff survey of caregivers described problematic encounters with emergency medical personnel. Generally, medical personnel were unable to provide treatment to individuals with ASDs due to escalated behavior, such as screaming or throwing a tantrum. In some cases, the situation was resolved and treatment provided because a person familiar with ASDs was able to calm the individual.

Judicial Personnel May Misinterpret the Behaviors of Persons With ASDs

Characteristic behaviors, such as averting eye contact, lack of emotion, or echolalia, may complicate interactions with judicial personnel, such as judges, Commonwealth's attorneys, court clerks, and magistrates. If judicial personnel do not know that the person has an ASD or if they do not understand the disorder, they may misinterpret these behaviors as defiance or non-compliance, and indicative of guilt. Additionally, persons with ASDs may not understand the judicial system or the implications of what they say and do in the judicial setting. For example, in an interrogation setting, persons with ASDs may confess to something they did not do simply to please the interrogator. Ultimately, individuals may be wrongly convicted and sentenced. Serving time in a correctional facility can be exacerbated by an ASD because the behaviors and characteristics of individuals with ASDs can result in inappropriate treatment by cellmates.

MOST PUBLIC SAFETY PERSONNEL IN VIRGINIA HAVE NOT RECEIVED TRAINING ON ASDs

While some public safety agencies have begun to provide their personnel with ASD awareness training, most agencies have not. Additionally, training has been largely concentrated among law enforcement personnel and does not appear to have reached other areas of public safety. Still, fewer than half of Virginia's criminal justice academies report providing some type of ASD awareness training to law enforcement officers. ASD awareness training is offered on an ad-hoc basis through in-service sessions for EMS and fire personnel. Additionally, no systematic ASD awareness training appears to be available to judicial personnel.

ASD Awareness Training Often Available to Law Enforcement Officers, but Seldom to Other Public Safety Personnel

Basic training is the classroom and field training which new recruits complete before they begin working as officers.

In-service training is the classroom and field training which officers receive throughout their careers.

Law enforcement personnel in Virginia are more likely than other types of public safety personnel to have received training on ASDs. In a staff survey of the Commonwealth's criminal justice academies, 44 percent of responding academies reported providing ASD awareness during basic training. Of those, half reported also providing ASD awareness during in-service training. On average, these criminal justice academies have been providing their students with ASD awareness training for six years. In addition to the training provided by training academies, one State expert also offers workshops to law enforcement officers interested in ASD awareness. While these workshops have been held in several areas of the State, they are ad-hoc and must be requested by a local law enforcement agency.

Criminal justice academies train different types of personnel, including police officers, sheriffs, court security officers, jail personnel, and corrections personnel. As shown in Table 32, nearly two-thirds of the academies that provide training to court security officers offered ASD awareness during basic training, but only a third of those that train corrections personnel.

Table 32: Less Than Half of Responding Virginia Criminal Justice Academies Provide ASD Awareness Training

	Percent of Responding Academies Providing ASD Awareness	
Personnel	**Basic Training**	**In-service Training**
Court security officers	62.5%	12.5%
Jail personnel	46.7	20.0
Sheriffs	42.1	15.8
Police officers	38.1	19.1
Corrections personnel	33.3	0.0

Source: JLARC staff survey of Virginia's criminal justice academies, February 2009.

Other types of public safety personnel, such as EMS, fire, rescue, and judicial personnel, are less likely than law enforcement personnel to have received ASD awareness training. According to VDH's Office of Emergency Medical Services (OEMS, which regulates EMS agencies), EMS personnel are not required to receive specific training on ASDs, but in-service sessions on ASDs have been offered at the State's EMS training conference during the past few years. Virginia firefighting personnel are also not required to receive ASD training, and no known training session has been made available to this group; however, many such personnel have EMS certification and may have had the opportunity to participate in the ASD awareness sessions at the State's EMS training conference. Judicial personnel, such as judges, magistrates, court clerks, and Commonwealth's attorneys, are not required to receive any training on ASDs. Further, personnel at the Supreme Court of Virginia and Commonwealth's Attorneys' Services Council indicated to JLARC staff that ASD awareness training has not been offered through the training programs offered to judicial personnel by their agencies.

Rising Awareness of ASDs and Personal Interest Often Provide Catalyst for Training

Criminal justice academies that provide ASD awareness training usually cited their growing awareness of the disabilities and an officer's personal interest in ASDs as the primary catalysts for offering training. When asked to identify the primary factors that prompted them to offer ASD awareness training, 55 percent of academies responding to the staff survey pointed to the increasing prevalence of ASDs, while 46 percent cited an awareness of the risk of dangerous encounters with individuals with ASDs. In addition, approximately 36 percent of responding academies with an ASD awareness curriculum indicated that the personal interest of an officer, often someone with a child or other family member with an ASD, was a catalyst for the program. Academy personnel interviewed by JLARC staff also indicated that the individuals who led efforts to establish ASD awareness training and taught the courses were officers who had children with ASDs.

Absence of ASD Training Generally Results From Limited Focus on ASDs and Lack of State Requirement

Criminal justice academies that do not provide ASD training indicated that they have either never considered providing such training, or that the State does not require them to offer such training. Nearly three-quarters of these academies reported that they had never considered offering ASD training. In these academies, personnel may not perceive ASD awareness training to be necessary because they have not encountered individuals with ASDs, or may not realize that they have done so. Additionally, two-thirds of the academies not offering ASD awareness training indicated that the absence of a State requirement to offer such training influenced their decision not to offer training. These responses may indicate that even if personnel were more aware of ASDs, they may be unwilling to develop and offer ASD training in the absence of a State requirement to do so.

OPTIONS TO INCREASE AWARENESS OF ASDs AMONG PUBLIC SAFETY PERSONNEL

JLARC staff identified a variety of options to increase awareness of ASDs among Virginia's public safety personnel. A training program could take different shapes depending upon (1) which tool is selected to convey information, (2) which public safety personnel are targeted, and (3) whether training is optional or required. To guide its decision, the State could consider how it approached raising awareness about Alzheimer's disease among public safety personnel.

Virginia's Alzheimer's Awareness Training Could Be Used as Roadmap

Virginia has prior experience with raising awareness of a specific condition among public safety personnel with its Alzheimer's Disease Awareness training program. In implementing the Alzheimer's disease awareness program, policymakers chose from among many of the same elements available to design ASD awareness training, as shown in Table 33. In 1998, the General Assembly required the Department of Criminal Justice Services (DCJS) to establish training standards and publish a model policy for law enforcement personnel regarding Alzheimer's disease. DCJS implemented Alzheimer's disease awareness requirements for all new law enforcement officers. To do so, the agency partnered with the Alzheimer's Association to design curricular materials for use by law enforcement academies in their basic training programs; distributed carry cards to academies and agencies for dissemination to personnel; and developed a two-day in-service session offered several times a year at various locations around the State. Al though they are not required to participate in the in-service session, personnel can participate in this training to receive continuing education credits.

Table 33: Elements of the Alzheimer's Disease Awareness Program

Training Tools	Personnel to Receive Training	Mechanisms to Implement Training
Basic training	Law enforcement officers	*Code of Virginia* requires DCJS to propagate training requirements DCJS requires training DCJS makes training materials available
Carry cards	Law enforcement officers EMS, fire personnel Judicial personnel	DCJS makes training materials available
In-service workshop	Law enforcement officers EMS, fire personnel Judicial personnel	DCJS developed and offers workshop for continuing education credits

Source: JLARC staff analysis and interviews with State agencies and stakeholders.

DCJS has actively worked with the Department of Health-Office of Emergency Medical Services (VDH-OEMS) and Department of Fire Programs (VDFP) to provide this in-service training to EMS and fire personnel. Recently, DCJS has begun to offer Alzheimer's disease training to judicial personnel. Since 2001, DCJS has received an annual appropriation ranging from $50,000 to $75,000 to continue offering this awareness program.

Array of Training Tools Exists to Raise ASD Awareness

JLARC staff identified a variety of training tools that could be used to raise awareness of ASDs among Virginia's public safety personnel (Table 34). Most of the training tools could be used individually or in combination with each other. In most cases the combination of more than one tool would enhance each tool's impact. For example, while providing officers with an in-service workshop about ASDs would increase their awareness, providing them with a short review session several months or years later could enhance the impact of the initial workshop.

Table 34: Variety of Tools Available to Raise ASD Awareness

Tool	Duration of Training
Carry card	None
Carry card review	5-7 min
Informational session	20 min
Video	30 min
Basic training workshop	2 hr
In-service workshop	2 hr

Source: JLARC staff analysis.

The tools described all aim to raise public safety personnel's awareness of ASDs, but the first four options are less intensive and provide only vital information. A carry card would be a small laminated card that contains critical information about signs of an ASD, potential adjustments that officers may make in approaching a person with an ASD, and ASD awareness resources. These cards would be distributed to personnel who would keep them in their possession while on duty. The information contained on carry cards could be reviewed during a brief (five to seven minute) session during which personnel could discuss questions or situations involving individuals with ASDs. This short session could take place at weekly staff meetings, and would provide more context, background, and reinforcement than just handing out the carry card. An informational session would provide officers with a short overview of ASDs, common characteristics and behaviors of persons with ASDs, and suggestions on how to work individuals on the autism spectrum.

ASD awareness could also be built by using training videos for public safety personnel, which are readily available. North Carolina has used this tool to train its law enforcement officers about ASDs. The state partnered with the Autism Society of North Carolina, a nationally recognized expert on ASDs, and public safety personnel to produce a video which was distributed to all law enforcement academies in the state. North Carolina is in the process of producing a similar video for use by judicial personnel. This video provides trainees the opportunity to observe characteristics and behaviors typical of individuals with ASDs, and watch how encounters with individuals on the autism spectrum might unfold. Additionally, a video presentation makes ASD training accessible to all agencies and academies, regardless of whether an instructor is available.

The last two options are more intensive and would provide personnel with a greater depth of information. A two-hour workshop, whether provided during basic or in-service training could address a broader range of issues in greater detail. The workshop may involve viewing a video about ASDs, and a discussion of hypothetical situations involving individuals with ASDs. This format may better prepare personnel to encounter individuals with ASDs, but they are the most resource-intensive training options and would require either additional training time or reducing training time currently devoted to other issues. Further, a qualified instructor would be needed.

In addition to the statewide options identified above, agencies could also implement a variety of creative programs to raise awareness of ASDs among their personnel. These programs may involve bringing parents of children with ASDs to speak with personnel, having officers spend time in an ASD classroom at a local school, or inviting individuals with ASDs and their families to tour stations and meet personnel. As will be described in the last section of this chapter, these community-based efforts not only provide first-hand exposure to ASDs for public safety personnel, they also provide an opportunity for people with ASDs and their families to forge relationships with public safety personnel and potentially reduce anxieties.

Training Could Be Made Available Only to Certain Public Safety Personnel

While all public safety officers could benefit from ASD awareness training, certain types of public safety personnel could be prioritized for training. The nature of law enforcement work requires officers to carry weapons, which can quickly turn an incident into a dangerous situation. Such severe potential consequences may speak to prioritizing training for law enforcement officers over other types of public safety personnel. This view was embraced by a nationally-recognized expert on ASD awareness training for public safety personnel interviewed by JLARC staff, and by most (78 percent) respondents to a JLARC staff survey of criminal justice academies.

Among states that have implemented ASD awareness training for public safety personnel, North Carolina and Illinois have provided training for law enforcement as a first step. Now that North Carolina's ASD awareness training is well established for its law enforcement personnel, the state is developing training for its judicial personnel. Indiana initially required ASD awareness training for only EMS and law enforcement officers working in schools, but is now considering legislative action to expand the requirement to all law enforcement and fire personnel. New Jersey has required ASD awareness training for all public safety personnel since the inception of the program.

Mechanism Used to Introduce Training Will Affect Utilization

If the State elects to promote ASD awareness among public safety personnel, it must be decided whether personnel will be required to receive training, or if the State will simply encourage training. Requiring training could be achieved in two ways: (1) the General Assembly could elect to mandate ASD training by statute, or (2) in the absence of a specific requirement in the *Code of Virginia*, the executive agencies responsible for regulating training for the various public safety personnel could promulgate regulations requiring ASD training.

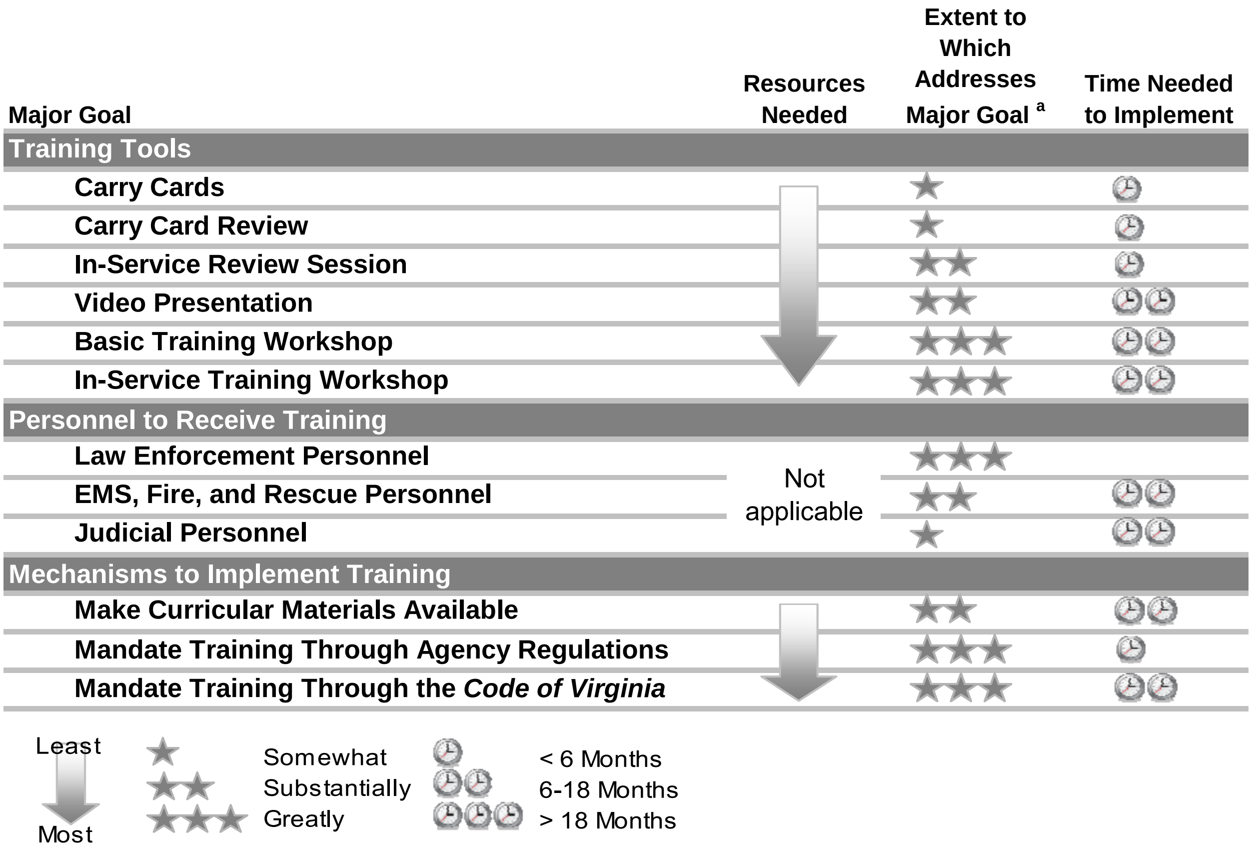
Instead of requiring ASD training, the Commonwealth could encourage building ASD awareness training by making materials available to agencies and academies. However, it is unclear whether training agencies would utilize these materials. As previously described, two-thirds of criminal justice academies that do not currently have ASD awareness training cited the lack of a State requirement as a primary reason for not providing training.

Some states, including Indiana, Illinois, and New Jersey have implemented ASD awareness training for public safety personnel via an addendum to state laws; however, other states, such as North Carolina and California, appear to have opted to implement ASD training for public safety personnel without a mandate. In both North Carolina and California, state agencies developed and disseminated ASD awareness training materials to law enforcement academies and agencies.

Summary of Options to Promote Awareness of ASDs Among Virginia Public Safety Personnel

In addition to having different policy merits, options described in this chapter vary in terms of the financial and human resources required, the extent to which they address the issues discussed in this chapter, and the time needed for implementation. Figure 24 summarizes these implementation considerations and reflects the best judgment of JLARC staff based on discussions with experts and knowledge gained during this review. To facilitate the State's decision whether and how to promote awareness of ASDs among Virginia public safety personnel, DCJS, VDH, and the Supreme Court of Virginia should collaborate with relevant stakeholders to weigh policy and implementation considerations, and identify which options are most suitable to reshape the training programs administered by their agencies.

Figure 24: Implementation Considerations for Options to Increase Awareness of ASDs Among Public Safety Personnel



Major Goal	Resources Needed	Extent to Which Addresses Major Goal [a]	Time Needed to Implement
Training Tools			
Carry Cards	↓	★	🕒
Carry Card Review		★	🕒
In-Service Review Session		★★	🕒
Video Presentation		★★	🕒🕒
Basic Training Workshop		★★★	🕒🕒
In-Service Training Workshop		★★★	🕒🕒
Personnel to Receive Training			
Law Enforcement Personnel	Not applicable	★★★	
EMS, Fire, and Rescue Personnel		★★	🕒🕒
Judicial Personnel		★	🕒🕒
Mechanisms to Implement Training			
Make Curricular Materials Available	↓	★★	🕒🕒
Mandate Training Through Agency Regulations		★★★	🕒
Mandate Training Through the *Code of Virginia*		★★★	🕒🕒

Least ↓ Most

★	Somewhat	🕒	< 6 Months
★★	Substantially	🕒🕒	6-18 Months
★★★	Greatly	🕒🕒🕒	> 18 Months

[a] Ratings reflect the extent to which each option addresses the major goal described in the gray-shaded row.

Source: JLARC staff analysis of research literature, other states' practices, and interviews with State agencies.

Recommendation (18). The Department of Criminal Justice Services should collaborate with relevant stakeholders to (1) evaluate the options for promoting awareness of autism spectrum disorders among law enforcement personnel; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

Recommendation (19). The Virginia Department of Health should collaborate with relevant stakeholders to (1) evaluate the options for promoting awareness of autism spectrum disorders among emergency medical services, fire, and rescue personnel; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

Recommendation (20). The Supreme Court of Virginia should collaborate with relevant stakeholders to (1) evaluate the options for promoting awareness of autism spectrum disorders among judicial personnel; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

TRAINING INDIVIDUALS WITH ASDs AND THEIR CAREGIVERS COULD IMPROVE INTERACTIONS WITH PUBLIC SAFETY PERSONNEL

Individuals with ASDs and their families may also benefit from receiving information about public safety personnel and how to interact with them. Even when public safety personnel receive ASD awareness training, they may not recognize a person as having an ASD. As a result, experts indicate that individuals with ASDs and their families should disclose this information to public safety personnel as quickly as possible. Providing individuals with ASDs the opportunity to learn about public safety personnel, their standard procedures, and the expected behaviors when an interaction occurs may reduce behavior escalation and help prevent difficult interactions from occurring later.

Several jurisdictions, including some in Virginia, have worked to help familiarize individuals with ASDs with public safety personnel by arranging structured interactions. For example, an ASD class or a local ASD organization may have an organized field trip to the local police station where individuals can meet police officers, tour the police station and police car, learn about appropriate interactions with police officers, and even take part in role playing.

The role playing activity might involve teaching individuals how to disclose their disability to personnel in an emergency situation.

Families may also choose to take proactive steps to disclose an individual's diagnosis before a situation arises. For example, parents may place autism bumper stickers, magnets, or license plates on their vehicles to alert public safety personnel to the potential that an individual with an ASD may be present. Individuals with ASDs can also wear medical alert jewelry, autism alert tags on their clothing, or autism alert temporary tattoos.

Chapter 10

Conclusions and Funding Options

In Summary

While several programs exist to support Virginians with ASDs and their families, they do not fully meet the needs of those who have extensive impairments, require supports from programs that have limited funding, or fail to meet eligibility criteria. If Virginia chooses to build a more effective and comprehensive system of care for these individuals, priority could be given to ensuring that existing resources are used as efficiently as possible, publicly supported programs have the tools to deliver effective services, and service gaps are alleviated for individuals who are currently unserved or underserved. In particular, intensive early intervention services could be provided to improve outcomes of individuals with ASDs and reduce future State expenditures. To achieve meaningful improvements while recognizing fiscal constraints, the State could implement pilot projects and focus on specific aspects of the service delivery system. To fund options it wishes to implement, Virginia could leverage Medicaid federal matching funds, use federal stimulus money to identify promising practices through pilot projects, explore a local match for waiver and employment services, reconsider mandated health insurance benefits, or require personal contributions.

As discussed throughout this report, there are numerous opportunities to improve Virginia's service delivery system for individuals with ASDs and their families, and several options to address each issue. Given the reality of finite resources and competing priorities, the State will need to consider the extent to which the issues affecting persons with ASDs should be addressed. This chapter offers a framework that could be used to prioritize initiatives, and guidance that could be followed to achieve meaningful improvements while balancing the fiscal constraints facing the State. In addition, State dollars need not be the exclusive funding source for implementing the options described in this report: the role of other public and private sources could also be explored to share the cost of better meeting the needs of Virginians with ASDs and their families in a fair and appropriate manner.

DESPITE EXISTING PROGRAMS, NEEDS OF SOME VIRGINIANS WITH ASDs ARE NOT FULLY MET

Virginia operates an array of publicly supported programs that provide important services but still cannot fully meet the needs of some Virginians with ASDs. In particular, service gaps exist for individuals with ASDs who need services that extend beyond the scope of existing programs, seek supports from programs that have limited funding, or fail to meet eligibility criteria. While service gaps exist at all life stages, they appear to be especially pronounced among adults.

The Early Intervention Part C program, which serves young children with ASDs and their families, is neither designed nor funded to provide the types or intensity of services that have been shown to maximize long-term outcomes and minimize societal costs. School-age children may not consistently receive services that adequately meet their multifaceted needs and enable them to achieve independence, which is a stated program goal. School Part B services focus largely on improving children's functioning in the school rather than in the home or community, where symptoms often manifest. Furthermore, schools are obligated to provide only an "appropriate" rather than an optimal education, and are not consistently planning and providing services to help students successfully transition to adulthood.

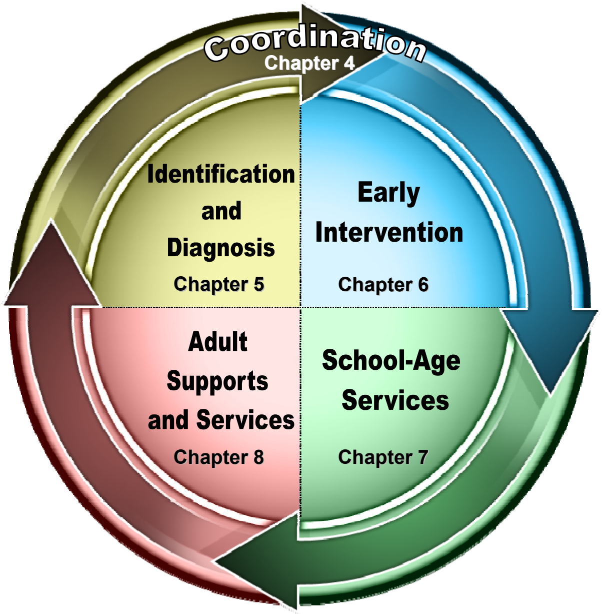
While the Comprehensive Services Act can supplement the array of services offered by schools, children are entitled only to services in their Individualized Education Programs (which address primarily educational needs), unless they are in foster care or at risk of foster care placement. Several programs exist to provide employment supports to adults with ASDs, but funding constraints limit the number of clients who can be served. Beyond employment supports, adults with ASDs have access to few services, such as housing or transportation assistance, that can help them live as independently as possible.

While waiver programs offer a wide range of services that can supplement other programs supporting Virginians with ASDs of all ages, eligible individuals may wait up to seven years before they can enroll in a comprehensive waiver program because of the limited number of slots. In addition, waiver services are available only to individuals with pronounced functional impairments, which may exclude higher-functioning individuals such as those with Asperger's syndrome. Adults with ASDs must also earn less than $1,900 per month (in 2008) in order to remain eligible for services.

STRATEGIC FRAMEWORK FOR PRIORITIZING ACTIONS TO IMPROVE VIRGINIA'S SERVICE DELIVERY SYSTEM

The options discussed in this report aim to improve Virginia's ability to meet the needs of Virginians with ASDs during each of four major life stages, while better coordinating services across all providers involved in plans of care (Figure 25). The options for addressing the issues described in Chapters 4 through 8 can be grouped into three broad categories: they all improve the system of care by (1) fostering greater efficiency, (2) bolstering effectiveness, or (3) alleviating service gaps. If Virginia chooses to take steps to improve its system of care for individuals with ASDs, it could begin by ensuring that existing resources are used as efficiently as possible. The next step could be to provide existing programs with the tools needed to administer effective services. Once existing programs are fulfilling their current mission as efficiently and effectively as possible, Virginia could then explore building a more comprehensive system of care by addressing gaps in the intensity and availability of services.

Figure 25: Report Options Address Improving Delivery and Coordination of Services Across Major Life Stages



Source: JLARC staff graphic.

Enhancing Efficiency

The efficiency of Virginia's service delivery system for individuals with ASDs could be enhanced through several initiatives to foster greater coordination and collaboration. First, because it has been designated the lead agency for all developmental disability services, the Department of Behavioral Health and Developmental Services (BHDS) could play a critical role in coordinating the extensive network of agencies and programs that serve individuals with ASDs. In its new role, the agency could identify opportunities to reduce duplicative services, rationalize and integrate similar programs, and reallocate resources toward the most effective initiatives. To ensure that the agency moves forward in a direction that adequately represents the interests of Virginians with ASDs and aligns with the vision of both the legislative and executive branches, BHDS should create a detailed action plan that addresses key priorities, including those discussed in this report, and present its findings to the Secretary of Health and Human Resources, the Joint Commission on Health Care, and the House Appropriations and Senate Finance Committees. This plan should be developed collaboratively with all relevant ASD stakeholders such as individuals with developmental disabilities (including ASDs), caregivers, organizations with expertise in ASDs such as Commonwealth Autism Service, other State agencies and entities, and experts in ASDs from Virginia Commonwealth University and the University of Virginia.

Recommendation (21). The Department of Behavioral Health and Developmental Services should create a detailed action plan reflecting the input of relevant stakeholders and the evaluation of options conducted by other State agencies, which specifies how the department will address the issues contained in this report and build a more effective system of care for Virginians with developmental disabilities, including autism spectrum disorders. This plan should be presented to the Secretary of Health and Human Resources, the Joint Commission on Health Care, and the House Appropriations and Senate Finance Committees no later than November 30, 2010.

In addition, a centralized and comprehensive information repository should be developed to help educate families and providers about ASDs, effective treatment options, and available programs. Through this resource, individuals with ASDs may learn about programs for which they are eligible, receive more appropriate services, and initiate interventions earlier when outcomes can be most easily shaped.

Bolstering Effectiveness

Existing programs could better meet the needs of Virginians with ASDs and more effectively shape outcomes if they had the tools to apply best practices, measure progress, and work toward common goals. Providers across the service delivery system could benefit from additional training and guidance about selecting and implementing research-based practices that have demonstrated success. In addition, more emphasis could be placed on using data to measure progress and adjust plans of care to ensure that they achieve the intended results. Comprehensive plans of care drafted by multidisciplinary teams could also facilitate access to needed interventions by helping families and providers better understand the full array of services needed, which publicly supported programs could be used, and where personal resources might be required to optimize outcomes. Lastly, case management services that coordinate the work of all providers could help ensure that services aim to achieve a common purpose and collectively meet as many needs as possible.

Alleviating Service Gaps

A comprehensive system of care could help a larger number of Virginians with ASDs receive services that more fully meet their needs. Even if publicly supported programs were more efficient and effective, some individuals with ASDs would likely still remain unserved or underserved. BHDS should facilitate the development of a State vision regarding the services that could be made available, and the resources needed to achieve this vision. Further, BHDS should provide leadership in designing and building the most appropriate system of care.

While a more comprehensive system of care could benefit individuals with ASDs of all ages, the provision of intensive early intervention services has been shown to offer the greatest potential for improving long-term outcomes while reducing costs to the State.

Service gaps could first be addressed in the early intervention system. While a more comprehensive system of care could benefit individuals with ASDs of all ages, the provision of intensive early intervention services has been shown to offer the greatest potential for improving long-term outcomes and could result in significant cost savings to the State and society. Because intensive early intervention will not succeed in eliminating the need for supports among all individuals with ASDs, providing appropriate employment services to adults could play an important role in maximizing the degree of independence and productivity they can achieve. In addition, Virginia should ensure that the services and supports in place to help further integrate individuals with disabilities in the community also address the unique needs of adults with ASDs.

Creating a regional office structure could also address many service gaps as well as streamline and further integrate the State's system of care. Regional offices could provide many of the critical services identified as lacking in Chapters 4 through 8 (including case management, multidisciplinary assessments, comprehensive plans of care, and direct ASD services) in a setting that is centralized and easily accessible. While alternatives exist, CSBs appear to be the most logical choice for assuming this role, given their relationship to BHDS and current role as service providers to individuals with intellectual disabilities. However, CSBs will likely be challenged to handle this additional responsibility given the concerns raised in 2008 by BHDS's Inspector General regarding the adequacy of services they deliver.

POTENTIAL APPROACH FOR IMPLEMENTING OPTIONS

If the State chooses to address issues affecting the delivery of services to Virginians with ASDs, several strategies could be followed to achieve meaningful results while acknowledging fiscal constraints. These strategies have been either used or recommended in several other states that have recently explored options to improve their service delivery system.

- Start with “quick hits” that require limited resources and have a short implementation timeframe to begin helping families right away.
- Build upon existing programs whenever possible in order to minimize the need for ramp-up in knowledge and resources, and expedite implementation.
- Implement pilot projects to identify successful initiatives which can be expanded when funding is more widely available.
- Focus efforts on specific programs or populations as a starting point.

FUNDING ALTERNATIVES TO IMPLEMENT OPTIONS

Several of the options contained in this report would require additional resources. While Virginia may choose to use general funds to implement options it wishes to exercise, other public and private sources could also be explored. In addition, the State could reinvest savings derived from its efforts to increase the efficiency of existing programs.

Medicaid Funding

Implementing options that involve Medicaid programs would enable Virginia to receive federal matching funds for at least 50 percent of expenditures (the federal matching rate is higher between October 2008 and December 2010 due to the American Recovery and Reinvestment Act). In particular, increasing the number of Individual and Family Developmental Disabilities Support (DD) and Mental Retardation (MR) waiver slots could help many individuals with ASDs receive comprehensive care during all life stages. The 2009 General Assembly tasked the Governor with creating a plan to reduce the urgent care waiting list for the MR waiver and the entire waiting list for the DD waiver by 20 percent prior to 2012, and eliminating these lists altogether before the 2018-2020 biennium. While this plan does not commit the State to allocating resources, it acknowledges the potential for this option to better meet the needs of Virginians with developmental disabilities while leveraging federal funds.

American Recovery and Reinvestment Act Funding

The American Recovery and Reinvestment Act (ARRA), otherwise known as the federal stimulus package, could also be used in the short term to implement options for better meeting the needs of Virginians with ASDs. According to the State’s 2009-2010 budget, a substantial portion of stimulus funding will be allocated to programs that support individuals with ASDs:

- $10.3 million for Early Intervention Part C programs,
- $9.5 million for preschool initiatives under School Part B program,
- $218.4 million for other special education purposes under the School Part B program,
- $11.6 million for vocational rehabilitation, and
- $0.3 million for centers for independent living (CILs).

While limited in duration, a portion of these funds could be used to initiate pilot projects to identify successful practices, which Virginia could subsequently choose to expand with other funding.

Reinvested State Savings

If the State chooses to implement options to maximize the efficiency of existing programs, resulting savings could be reinvested to improve the effectiveness of existing programs as well as address service gaps. In addition, research has shown that investing in intensive early intervention services could result in significant long-term cost reductions for the State, which could also be used to fund improvements in Virginia's system of care for individuals with ASDs.

Local Government Funding

Local governments could also allocate additional funding to programs that support individuals with ASDs. While localities pay for a substantial portion of School Part B and CSA expenditures, and sometimes choose to contribute to the Early Intervention Part C program and CILs, they do not appear to contribute to other programs such as Medicaid waivers or vocational rehabilitation. Virginia could re-examine the extent to which localities should support program expenditures, or require local matching funds for new services. This approach would be consistent with other programs, such as CSA, where Medicaid-funded services require a local match. In addition, building a more effective and comprehensive system of care could reduce the need for special education services and therefore reduce the expenditures of local governments, which pay nearly two-thirds of School Part B expenditures.

Health Insurance Coverage

While the cost of serving individuals with ASDs is currently borne primarily by publicly supported programs and personal resources, steps could be taken to increase the role of health insurance coverage in paying for medically necessary services. Several states have chosen to override the objections of health insurers described in Chapter 3 by enacting comprehensive mandated health benefits legislation covering all ASD-related therapies, including speech, occupational, physical, and behavioral interventions. As of May 2009, 13 states (Arizona, Connecticut, Florida, Illinois, Indiana, Louisiana, Montana, Nevada, New Jersey, New Mexico, Pennsylvania, South Carolina, and Texas) had enacted such legislation. Bills had been introduced in another 25 states in 2009, including Virginia. Further, a bill was introduced in the U.S. Congress in April 2009 that would compel comprehensive coverage of research-based, medically necessary ASD therapies (including applied behavior analysis) by health insurance plans not governed by State laws.

Legislation mandating health insurance benefits for individuals with ASDs was not enacted in Virginia largely due to concerns over the fiscal impact of rising premiums on small businesses and the State; disagreements over the nature of ASD interventions as educational rather than medical; a lack of a mechanism to ensure that only effective practices are used; and difficulties ensuring the qualifications of providers. However, it appears that other states have found ways to mitigate several of these issues. For example, California issued guidelines to more clearly delineate the responsibilities of schools toward meeting educational needs and health insurers for covering medically necessary services. California also recommended creating an advisory council of medical and allied health professionals who would be responsible for identifying the practices that effectively treat ASDs and would be reimbursable by health insurers. In addition, several states, including Pennsylvania, have created a certification to ensure minimum qualifications for providers of behavioral interventions, such as ABA.

Personal Resources

To defray a portion of the costs associated with better meeting the needs of individuals with ASDs, Virginia could require the contribution of personal resources based on ability to pay. While the School Part B program entitles families to special education services and supports at no cost, other programs are not subject to this requirement. The State could therefore evaluate whether the program fees currently charged to individuals with ASDs and their caregivers are adequate, and use any appropriate increase in individual contributions to provide better or more services. Alternatively, Virginia could require personal contributions only for new services it wishes to implement.

List of Recommendations:

Assessment of Services for Virginians With Autism Spectrum Disorders

1. The Department of Behavioral Health and Developmental Services should collaborate with relevant State agencies and stakeholder groups to design a centralized, comprehensive, and reliable source of information to educate Virginians about (1) autism spectrum disorders, (2) research findings about treatment approaches and interventions, (3) publicly supported programs and supports, (4) private providers specializing in autism spectrum disorders, (5) support groups, and (6) any other relevant information identified by stakeholders. The department and stakeholders should determine the mechanism most suitable for delivering this information, such as a guidebook, website, or staffed clearinghouse, and the entity best suited to create and administer the mechanism selected.

2. The Department of Behavioral Health and Developmental Services should collaborate with relevant stakeholders to (1) evaluate the options for promoting State-level accountability and coordination of services for Virginians with autism spectrum disorders, enhancing access to information about community resources, and improving the coordination of individual care; and (2) identify no later than March 31, 2010, which, if any, options are most beneficial to pursue.

3. The Department of Behavioral Health and Developmental Services should collaborate with relevant stakeholders to (1) evaluate the options for raising public awareness about autism spectrum disorders, increasing consistent and standardized screenings, expediting diagnoses, and improving the referral process; and (2) identify no later than March 31, 2010, which, if any, options are most beneficial to pursue.

4. The Department of Medical Assistance Services should develop and implement a plan for educating Virginians with autism spectrum disorders (ASDs) and their families; Medicaid case managers; providers; and personnel from relevant programs including School Part B, Early Intervention Part C, and Comprehensive Services Act about the availability of Medicaid waivers and programs through which needed services can be

obtained. In particular, outreach efforts should convey that individuals with ASDs may be eligible for the Elderly or Disabled with Consumer Direction waiver, and that Medicaid and waiver recipients under age 21 can receive a comprehensive array of medically necessary services through the Early and Periodic Screening, Diagnosis, and Treatment program. The department should present a detailed plan outlining its proposed outreach efforts to the Joint Commission on Health Care no later than November 30, 2009.

5. The Department of Behavioral Health and Developmental Services should collaborate with relevant stakeholders to (1) evaluate the options for enhancing the early intervention system for children with autism spectrum disorders by improving the Early Intervention Part C program and developing services through regional offices; and (2) identify no later than March 31, 2010, which, if any, options are most beneficial to pursue.

6. The Department of Education should collaborate with relevant stakeholders to (1) evaluate the options for enhancing the early intervention system for children with autism spectrum disorders by improving the Part B special education services available to preschool-age children and offering educational alternatives through a scholarship program; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

7. The Department of Medical Assistance Services should collaborate with relevant stakeholders to (1) evaluate the options for enhancing the early intervention system by improving the Medicaid programs serving young children with autism spectrum disorders; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

8. The Virginia Department of Education should collaborate with the Office of the Attorney General to develop operational guidelines for schools on the provision of a free and appropriate public education for students with disabilities, as determined by federal and state legal decisions.

9. The Department of Education should develop a model individualized education program (IEP) for Virginia students with autism spectrum disorders. The model IEP should include guidance on (1) developing appropriate and measurable goals and objectives; (2) addressing all major domains of functioning for students with autism spectrum disorders, including behavior, communication, sensory, and cognitive skills; (3) building social and life skills; and (4) fostering generalization of skills to environments other than the school.

10. The Department of Education should create transition guidelines that offer strategies for addressing the unique and complex needs of high school students with autism spectrum disorders; securing the services needed to build life, social, and vocational skills; and positioning them for pursuing opportunities of their choice after these students exit the school system.

11. The Department of Education should collaborate with relevant stakeholders to (1) evaluate the options for improving the delivery of services to school-age children with autism spectrum disorders by increasing the consistency of service provision, enhancing its professional development programs, developing goals and objectives and monitoring progress, improving transition services, and offering educational alternatives through a scholarship program; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

12. The Department of Medical Assistance Services should collaborate with relevant stakeholders to (1) evaluate the options for improving the delivery of services to school-age children with autism spectrum disorders by increasing knowledge about Medicaid services, developing standards and rates for Medicaid providers, and adjusting existing or creating new waiver programs; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

13. The Department of Behavioral Health and Developmental Services should collaborate with relevant stakeholders to (1) evaluate the options for improving the delivery of services to school-age children with autism spectrum disorders by developing services through regional offices; and (2) identify no later

than March 31, 2010, which, if any, options are most beneficial to pursue.

14. The General Assembly may wish to consider directing the Olmstead Community Integration Implementation Team to include in its action plan and implementation update a discussion of steps that can be taken to help Virginians with autism spectrum disorders achieve greater levels of independence and be further integrated in the community.

15. The Department of Rehabilitative Services should collaborate with relevant stakeholders to (1) evaluate the options for fostering greater independence among adults with autism spectrum disorders by improving employment services and supports; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

16. The Department of Medical Assistance Services should collaborate with relevant stakeholders to (1) evaluate the options for fostering greater independence among adults with autism spectrum disorders by improving Medicaid waiver programs; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

17. The Department of Behavioral Health and Developmental Services should collaborate with relevant stakeholders to (1) evaluate the options for fostering greater independence among adults with autism spectrum disorders; and (2) identify no later than March 31, 2010, which, if any, options are most beneficial to pursue.

18. The Department of Criminal Justice Services should collaborate with relevant stakeholders to (1) evaluate the options for promoting awareness of autism spectrum disorders among law enforcement personnel; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

19. The Virginia Department of Health should collaborate with relevant stakeholders to (1) evaluate the options for promoting

awareness of autism spectrum disorders among emergency medical services, fire, and rescue personnel; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

20. The Supreme Court of Virginia should collaborate with relevant stakeholders to (1) evaluate the options for promoting awareness of autism spectrum disorders among judicial personnel; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

21. The Department of Behavioral Health and Developmental Services should create a detailed action plan reflecting the input of relevant stakeholders and the evaluation of options conducted by other State agencies, which specifies how the department will address the issues contained in this report and build a more effective system of care for Virginians with developmental disabilities, including autism spectrum disorders. This plan should be presented to the Secretary of Health and Human Resources, the Joint Commission on Health Care, and the House Appropriations and Senate Finance Committees no later than November 30, 2010.

Appendix A Study Mandate

HOUSE JOINT RESOLUTION NO. 105

Directing the Joint Legislative Audit and Review Commission to study autism services in the Commonwealth. Report.

Agreed to by the House of Delegates, February 8, 2008
Agreed to by the Senate, March 4, 2008

WHEREAS, autism spectrum disorders (ASDs) are a group of developmental disabilities defined by significant impairments in social interaction and communication and the presence of unusual stereotypical or repetitive behaviors, interests, and activities that often appear before the age of three and affect all racial, ethnic, and socioeconomic groups; and

WHEREAS, many people with ASDs also have unusual ways of learning, paying attention, or reacting to different situations and sensations, and the thinking and learning abilities of people with ASDs can vary significantly; and

WHEREAS, the Center for Disease Control's Autism and Developmental Disabilities Monitoring Network reports that the rate of autism among the population has grown by 173% over the past decade, and that in 2007, one in every 150 eight-year-old children had a diagnosed ASD; and

WHEREAS, between 1998 and 2006, the number of children aged three to 22 with an identified ASD enrolled in the Virginia Public School System increased by more than 400%, from 1,521 to 6,753; and

WHEREAS, law-enforcement officers, public safety personnel, first responders, judges, magistrates, attorneys for the Commonwealth, public defenders, and various personnel involved in the legal system may not be aware of the impacts of ASDs or of the best ways to assist individuals with ASDs; and

WHEREAS, providing education and training to such persons will result in less disruptive, more meaningful interactions for all persons involved and better and more equitable services for persons with autism; and

WHEREAS, the need for uniform, consistent, effective, and appropriate approaches to the diagnosis, treatment, and management of ASDs has grown apace with the prevalence of ASDs; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Joint Legislative Audit and Review Commission be directed to study autism services in the Commonwealth.

In conducting its study, the Joint Legislative Audit and Review Commission shall (i) assess current availability and delivery of autism services in the Commonwealth; (ii) identify best practices in the diagnosis, treatment, and management of ASDs; (iii) evaluate the need and means to disseminate information collected during assessments to relevant service areas including education, law enforcement, rehabilitation, mental health, and emergency services; (iv) assess service delivery in other states; (v) identify current autism educational and training opportunities available to or provided to law-enforcement and judicial personnel, including law-enforcement officers, public safety personnel, first responders, judges, magistrates, attorneys for the Commonwealth, public defenders, and other personnel involved in the legal system; (vi) identify best practices and areas for improvement in autism education and training for law-enforcement and judicial personnel, and other models for providing autism education for law-enforcement and judicial personnel; and (vii) recommend ways to improve the delivery of autism services in the Commonwealth, including methods of providing the range of autism educational and training opportunities to law-enforcement and judicial personnel.

All agencies of the Commonwealth shall provide assistance to the Joint Legislative Audit and Review Commission for this study, upon request. In addition, the Joint Legislative Audit and Review Commission may seek input from the Secretary of Health and Human Services, the Secretary of Education, Commonwealth Autism Services, the Joint Commission on Health Care, the Virginia Institute of Autism, and other interested stakeholders.

The Joint Legislative Audit and Review Commission shall complete its meetings for the first year by November 30, 2008, and for the second year by November 30, 2009, and the Director 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 next Regular Session of the General Assembly for each year. Each executive summary shall state whether the Joint Legislative Audit and Review Commission 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 summaries and reports 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.

Appendix B Research Activities and Methods

Key research activities for this study included

- site visits to local Early Intervention Part C programs, school divisions, regional special education programs, vocational rehabilitation field offices, and Centers for Independent Living;
- surveys of individuals with ASDs or their caregivers, Virginia public schools, and criminal justice academies that train law enforcement personnel;
- public input sessions;
- structured interviews with staff from State agencies, service providers, and other stakeholders;
- reviews of best practices used by other states to serve individuals with ASDs;
- reviews of the literature on autism spectrum disorders; and
- participation in professional conferences.

SITE VISITS

JLARC staff visited eight Virginia areas to conduct structured interviews with staff from entities that serve individuals with ASDs, including local Early Intervention Part C programs, school divisions, regional special education programs, Department of Rehabilitation Services (DRS) vocational rehabilitation (VR) field offices, and Centers for Independent Living (CILs). These site visits were conducted in December 2008 and January 2009, and each visit was completed in one to two days. In a few cases, interviews were handled over the phone to reduce time and costs associated with travel. Staff interviewed included Part C system managers, infant educators, special education directors, school division autism specialists, VR field office staff, and CIL staff. Topics discussed during site visits included

- estimates of individuals with ASDs who are served and their characteristics,
- types and adequacy of services that are provided to individuals with ASDs,
- types of and extent to which additional services are needed,

- qualifications of staff and other providers who serve individuals with ASDs,
- efforts to ensure the effectiveness of services, and
- barriers to serving individuals with ASDs.

The study team used several criteria to select the eight areas in which to conduct site visits (Figure B-1). Staff identified school divisions serving at least 10 students with ASDs, and then selected one school division from each of the eight School Superintendent regions which, collectively, represented urban, suburban, and rural areas, as well as varying levels of fiscal stress.

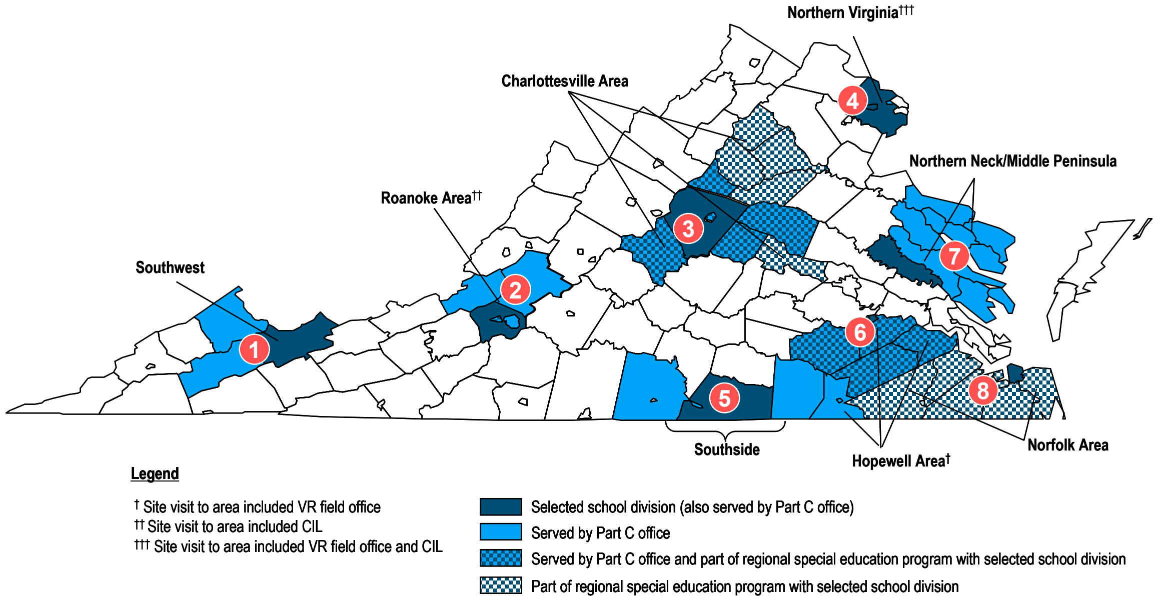
JLARC staff also conducted site visits or telephone interviews with agencies in several other areas of the State, including

- the Shenandoah Valley Special Education Regional Program,
- the Fairfax County VR field office,
- the Henrico County VR field office, and
- the Chesterfield County Public Schools Career and Transition Services office.

SURVEYS

JLARC staff administered three surveys targeting (1) individuals

Figure B-1: JLARC Staff Visited Eight Virginia Areas



Source: JLARC staff analysis.

with ASDs or their caregivers, (2) public schools in Virginia, and (3) criminal justice academies. Surveys were designed to supplement the information gathered during input sessions, site visits, structured interviews, and reviews of the literature.

Survey of Individuals With ASDs or Their Caregivers

JLARC staff surveyed individuals with ASDs or their caregivers to gather information on individuals with ASDs, the services they have received, and any barriers they or their families have faced in obtaining services. Survey topics included

- timeline for identifying and diagnosing the ASD, and difficulties obtaining them;
- information provided after obtaining a diagnosis;
- services received throughout life stages from publicly-funded early intervention, school-based, and other programs, including the adequacy of services;
- services secured with private funding and barriers to access; and
- levels of independence and productivity achieved by adults with ASDs and barriers to greater independence.

JLARC staff contacted all major ASD stakeholder groups and asked that they notify their members about the electronic survey, and 600 responses were received from individuals with ASDs or their caregivers.

Survey of Virginia Public Schools

To gather information on school-based services for students with ASDs, JLARC staff conducted a survey of a sample of preschool, elementary, middle, and high schools in Virginia. Survey topics included the types and intensity of services schools provide to students with ASDs, schools' ability to address the various functional needs of these students, the resources available to school personnel for developing and implementing appropriate education plans for these students, and the challenges schools face in meeting students' educational needs. JLARC staff surveyed a random sample of 560 schools out of 2,107 in Virginia, and received responses from 436 schools (78 percent of the sample).

Survey of Criminal Justice Academies

JLARC staff conducted a survey of the 36 criminal justice academies in Virginia. The purpose of this survey was to gather information on the extent to which criminal justice academies provide

ASD training to criminal justice personnel such as police officers, sheriffs, jail personnel, corrections personnel and court security officers. Survey topics included the provision of training, training recipients, catalysts for providing training, resources necessary to deliver training, and training content. Of the 36 academies surveyed, 27 provided responses (75 percent).

STRUCTURED INTERVIEWS

JLARC staff conducted a variety of interviews with personnel from State-level entities, service providers, and stakeholder groups, as well as State and national experts on topics such as public safety personnel training and employment supports for individuals with disabilities.

Interviews With Staff of State-Level Entities

JLARC staff interviewed staff of the following State-level entities to gain additional insight into the delivery of services to individuals with ASDs, the effectiveness of ASD treatment methods, problems experienced in obtaining services across life stages, the number of individuals with ASDs served, service costs, and the history of State policies for serving individuals with ASDs:

- Virginia Department of Behavioral Health and Developmental Services (formerly Mental Health, Mental Retardation and Substance Abuse Services),
- Virginia Department of Education and the Training and Technical Assistance Centers,
- Virginia Department of Health,
- Virginia Department of Medical Assistance Services,
- Virginia Department of Rehabilitative Services and the Woodrow Wilson Rehabilitation Center,
- Virginia Board for People with Disabilities,
- Joint Commission on Health Care, and
- Research and Rehabilitation Center on Workplace Supports and Job Retention at Virginia Commonwealth University.

JLARC staff also interviewed staff of several agencies that provide training to public safety personnel to gather information on issues involving individuals with ASDs and the availability of ASD training opportunities for public safety personnel:

- Virginia Department of Criminal Justice Services,
- Virginia Department of Health,

- Virginia Department of Fire Programs,
- Supreme Court of Virginia,
- Commonwealth's Attorney Services Council, and
- Roanoke County Criminal Justice Training Academy.

Interviews With Stakeholder Groups and Service Providers

JLARC staff conducted structured interviews with various stakeholder groups and service providers to gather information on health care professionals' diagnostic practices; professional opinions about service needs, adequacy of services, and effective practices; and suggestions for improving the delivery of services to Virginians with ASDs:

- Virginia's Commonwealth Autism Service,
- Virginia Autism Council,
- Virginia Treatment Center for Children at Virginia Commonwealth University,
- Virginia Chapter of the American Academy of Pediatrics,
- Virginia's Faison School for Autism, and
- Autism Speaks.

PUBLIC INPUT SESSIONS

Four JLARC staff-led public input sessions were held at the beginning of this review to assist JLARC staff in defining the issues faced by individuals with ASDs and their families when seeking services. Sessions were held in the fall of 2008 in Chesterfield County and the cities of Roanoke, Portsmouth, and Woodbridge, and 56 individuals provided formal comments. Staff posted an announcement on the JLARC website to notify individuals about the public input sessions. ASD stakeholder groups were also asked to post an internet link to the announcement on their website and distribute it to their members via e-mail. Individuals who could not attend the sessions could also submit written comments via e-mail, fax, or telephone, and 40 individuals provided input in this form.

REVIEW OF RESEARCH LITERATURE AND VIRGINIA POLICIES

JLARC staff reviewed numerous documents and studies to supplement and validate findings from interviews, site visits, and surveys. A review of the literature was conducted regarding the

- diagnostic process, specifically factors impacting delays in receiving a diagnosis, and the age when stable ASD diagnoses can be made;
- effectiveness of treating ASDs, particularly the impact of early intensive interventions;
- best practices in educational programs for students with ASDs, including training school personnel; and
- previous Virginia studies of the delivery of services to individuals with ASDs or other developmental disabilities.

Finally, JLARC staff reviewed State statutes and policies related to services for individuals with ASDs.

REVIEW OF BEST PRACTICES IN OTHER STATES

JLARC staff used a three-pronged approach to review best practices that other states have implemented. First, staff compiled information on policies and practices other states use to provide services to this population, including recent initiatives states have implemented or considered. Summaries of state efforts compiled by several national organizations such as the Easter Seals and the National Conference of State Legislatures were reviewed by staff. In particular, the Easter Seals website provided links to ASD-related task forces, programs, and legislation within each state.

Second, JLARC staff identified for further review programs or policies that have been implemented by other states that appeared to be promising practices for effectively and efficiently serving individuals with ASDs. For some programs, staff were able to gather evidence of program effectiveness through formal reports of program outcomes. However, many of these programs were newly implemented or had recently undergone significant changes. As a result, JLARC staff considered additional factors such as the extent to which the program contained components that had been identified by national organizations and experts in the field as effective for serving individuals with ASDs, used mechanisms to ensure program accountability, and had been replicated in other states. Lastly, JLARC staff contacted agency staff in other states to gather more detailed information about the programs that had been identified as best or promising practices.

PARTICIPATION IN PROFESSIONAL CONFERENCES

Project staff also participated in two professional conferences related to ASD services during the study. Staff attended a special education law conference focused on the implementation of IDEA as well as the eighth annual Autism Conference sponsored by the Commonwealth Autism Service.

Appendix **C**

Summary of Major Studies on Effectiveness of Early Intensive ASD Treatment

Group	Description	Outcomes: Average Gain in IQ Points	Outcomes: Educational Placement
EIBI compared to less intensive public school special education (2006 study)			
Treatment	21 children who received EIBI that was ABA-based (35 to 40 hours per week)	+25	▪ 29% fully included in regular class without supports ▪ 52% of children in regular class with supports
Comparison	21 children who received community-based interventions such as public school special education (15 to 30 hours per week)	+14	▪ 5% primarily in regular class
EIBI compared to less intensive parent-training model (2000 study)			
Treatment	15 children who received 30 hours of ABA-based therapy from therapists	+16	▪ 27% in regular class without supports
Comparison	13 children who received ABA-based therapy from parents in addition to special education (20 to 25 hours per week total)	-1	▪ No children in regular class without supports
EIBI compared to two groups who received less intensive treatment (1987 study)			
Treatment	19 children who received 40 hours of one-to-one ABA	▪ 47% achieved normal range IQ scores (94 to 120)	▪ 47% successful first grade performance in general class without supports ▪ 42% placed in special education classes for language delayed ▪ 11% placed in class for children with autism or MR
Comparison	19 children who received 10 hours or less of one-to-one ABA, same provider as treatment group 21 children who received 10 hours or less of one-to-one ABA, different provider than treatment group	▪ 2% achieved IQ in normal range	▪ 2% placed in general class without supports ▪ 45% placed in special education class for language delay ▪ 53% places in class for children with autism or MR

Source: JLARC staff review of literature on early intensive behavioral interventions.

Appendix D

Major Programs Serving Virginians With ASDs

Child Development Clinics

Program Description	Provide services to children suspected of having developmental or behavioral disorders. Services provided include diagnostic assessment, care planning, limited follow-up care coordination, referrals, and screening for the Individual and Family Developmental Disabilities Support waiver.
State Administrative Agency	Department of Health (VDH)
Local Administration	Local health departments and State universities.
Service Providers	Multi-disciplinary team comprised of a pediatrician, nurse, social worker, psychologist, and educational consultant employed by a local school division.
Referral Sources	Schools, local department of social services, physicians, families
Year Established	1955
Guiding Legislation	• *Code of Virginia* §32.1-12 and §32.1-77 • 12VAC5-191
Eligibility Criteria	**Age:** Under 21 years of age **Diagnostic:** suspected of or at-risk of developmental disability or behavioral disorder **Functional:** None **Financial:** None
Cost of Services	Co-payments based on VDH's sliding scale

Program Funding ($M)	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Federal	$1.92	$2.02	$1.78	$1.85
State	1.63	1.61	1.54	1.59
Local	-	-	-	-
Other	0.01	0.01	0.20	0.15
TOTAL	**$3.56**	**$3.63**	**$3.52**	**$3.59**

Individuals Served	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Total	**2,516**	**2,494**	**2,687**	**2,449**
With ASDs	n/a	n/a	n/a	n/a

Individual and Family Developmental Disabilities Support (DD) Waiver

Program Description	Provides comprehensive home and community-based care to individuals would otherwise require placement in an intermediate care facility for persons with mental retardation (ICF/MR).
State Administrative Agency	Department of Medical Assistance Services (DMAS)
Local Administration	Pre-admission assessments completed by child development clinics (CDCs) through local departments of health; local departments of social services determine financial eligibility.
Service Providers	Private providers generally, and some community services boards and local departments of health.
Referral Sources	Staff from local agencies, parents
Year Established	2000
Guiding Legislation	Social Security Act - Section 1915(c) Home and Community-Based Services Waivers
Max. Enrollment ('08)	608; 715 on waiting list as of May 2009
Eligibility Criteria	**Age:** 6 or older **Diagnostic:** developmental disability excluding intellectual disability **Functional:** meeting ICF/MR criteria based on dependency level in two or more categories of the "level of functioning survey" **Financial:** individual income below 300% of SSI benefits ($1,911 per month in 2008) and assets up to $2,000
Cost of Services	Co-payments required if income > 100% of SSI, up to 300% of SSI benefits if employed 20+ hours per week

Program Funding ($M)	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Federal	$5.32	$4.75	$4.15	$3.10
State	5.32	4.75	4.15	3.10
TOTAL	**$10.64**	**$9.50**	**$8.30**	**$6.20**

Individuals Served	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Total	**541**	**408**	**388**	**338**
With ASDs	316	213	212	200

Elderly or Disabled With Consumer Direction (EDCD) Waiver

Program Description	Provides home and community-based services to individuals who would otherwise require placement in a nursing facility. Services include personal care, respite care, adult day health care, personal emergency response system and medication monitoring.
State Administrative Agency	Department of Medical Assistance Services (DMAS)
Local Administration	Screening requested from local departments of social services or health; local departments of social services determine financial eligibility.
Service Providers	Private providers
Referral Sources	Staff from local agencies, parents
Year Established	2005
Guiding Legislation	Social Security Act - Section 1915(c) Home and Community-Based Services Waivers
Max. Enrollment ('08)	None
Eligibility Criteria	**Age:** > 65, or any if disabled **Diagnostic:** disability if under 65 **Functional:** meeting level of care requirement for admission into nursing home based on the "uniform assessment instrument" **Financial:** individual income below 300% of SSI ($1,911 per month in 2008) and assets up to $2,000
Cost of Services	Co-payments required if income exceeds 100% of SSI benefits

Program Funding ($M)	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Federal	$113.96	$95.31	$79.81	$68.57
State	113.96	95.31	79.81	68.57
TOTAL	**$227.92**	**$190.62**	**$159.62**	**$137.14**

Individuals Served	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Total	**16,159**	**13,965**	**12,588**	**11,901**
With ASDs	371	174	78	64

Mental Retardation (MR) Waiver

Program Description	Provides comprehensive home and community-based care to individuals who would otherwise require placement in an intermediate care facility for persons with mental retardation (ICF/MR).
State Administrative Agency	Departments of Medical Assistance Services (DMAS) and Behavioral Health and Developmental Services
Local Administration	Pre-admission assessments conducted by 40 community services boards (CSBs); local departments of social services determine financial eligibility.
Service Providers	CSBs or private providers
Referral Sources	Staff from local agencies, parents
Year Established	1991
Guiding Legislation	Social Security Act - Section 1915(c) Home and Community-Based Services Waivers
Max. Enrollment ('08)	7,852
Eligibility Criteria	**Age:** all **Diagnostic:** intellectual disability or, if under age 6, developmental disability **Functional:** meeting ICF/MR criteria based on dependency level in two or more categories of the "level of functioning survey" **Financial:** individual income below 300% of SSI ($1,911 per month in 2008) and assets up to $2,000
Cost of Services	Co-payments required if income > 100% of SSI, up to 300% of SSI benefits if employed 20+ hours per week

Program Funding ($M)	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Federal	$215.00	$190.93	$162.84	$140.18
State	215.00	190.93	162.84	140.18
TOTAL	**$430.00**	**$381.86**	**$325.68**	**$280.36**

Individuals Served	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Total	7,295	6,850	6,599	6,421
With ASDs	837	735	615	533

Wait List	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Total	**4,375**	**3,872**	**3,345**	**2,763**
Urgent	2,289	2,017	1,724	1,103
Non-Urgent	2,086	1,855	1,621	1,660

Day Support Waiver

Program Description	Provides training, assistance, and specialized supervision to enable individuals on the waiting list for the Mental Retardation waiver.
State Administrative Agency	Department of Medical Assistance Services (DMAS) and Department of Behavioral Health and Developmental Services
Local Administration	Pre-admission assessments conducted by 40 community services boards (CSBs); local departments of social services determine financial eligibility.
Service Providers	CSBs or private providers
Referral Sources	Staff from local agencies, parents
Year Established	2005
Guiding Legislation	Social Security Act - Section 1915(c) Home and Community-Based Services Waivers
Max. Enrollment ('08)	7,852
Eligibility Criteria	**Age:** all **Diagnostic:** intellectual disability diagnosis made by a licensed professional or, if under age 6, developmental evaluation must show developmental delay **Functional:** meeting ICF/MR criteria based on dependency level in two or more categories of the "level of functioning survey" **Financial:** individual income below 300% of SSI ($1,911 per month in 2008) and assets up to $2,000
Cost of Services	Co-payments required if income exceeds 100% of SSI benefits, up to 300% of SSI benefits if employed 20+ hours per week

Program Funding ($M)	SFY 08	SFY 07	SFY 06	SFY 05
Federal	$1.54	$1.48	$0.90	-
State	1.54	1.48	0.90	-
TOTAL	**$3.08**	**$2.96**	**$1.79**	**-**

Individuals Served	SFY 08	SFY 07	SFY 06	SFY 05
Total	270	265	227	-
With ASDs	33	25	18	-

Wait List	SFY 08	SFY 07	SFY 06	SFY 05
Total	**4,375**	**3,872**	**3,345**	**-**
Urgent	2,289	2,017	1,724	-
Non-Urgent	2,086	1,855	1,621	-

Early Intervention Part C Program

Program Description	Provides comprehensive supports and services focused on increasing the child's participation in family and community activities. Supports and services focus on coaching parents and other caregivers on finding ways to help the child learn during everyday activities.
State Administrative Agency	Department of Behavioral Health and Developmental Services (BHDS). The Virginia Interagency Coordinating Council (VICC) advises and assists BHDS.
Local Administration	BHDS contracts with 40 local lead agencies: 33 community services boards (CSBs), 2 public school divisions, 2 universities, 2 social service departments, and 1 local department of health. Local interagency coordinating councils (LICCs) advise and assist each local lead agency.
Service Providers	Local lead agencies or private providers with whom they contract
Referral Sources	Physicians, parents, staff from local agencies
Year Established	1986
Guiding Legislation	Individuals with Disabilities Education Act (IDEA) Part C – Infants and Toddlers with Disabilities
Eligibility Criteria	**Age:** under 3 **Diagnostic:** if no developmental delay, physical or mental condition with a high probability of resulting in a developmental delay **Functional:** functioning at a level 25% or more below their age or show atypical development **Financial:** none
Cost of Services	No cost to families for several core services, and sliding-scale based on ability to pay for others

Program Funding ($M)	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Federal	$11.20	$9.87	$8.86	$8.92
State	8.52	8.23	3.57	3.13
Local	8.37	7.43	5.41	-
Other	4.36	5.13	2.92	-
TOTAL	**$32.45**	**$30.65**	**$20.76**	**$12.04**

Individuals Served	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Total	**11,351**	**10,330**	**10,212**	**9,615**
With ASDs/Suspected ASDs	460	n/a	n/a	n/a

School Part B Program

Program Description	Provides appropriate educational services and supports to meet students with disabilities' unique needs and prepare them for further education, employment, and independent living.
State Administrative Agency	Department of Education (DOE.) The State Special Education Advisory Committee advises DOE.
Local Administration	134 local educational agencies (school divisions)
Service Providers	Public early childhood education centers and elementary, middle, and high schools; Head Start programs; private or other contract providers
Referral Sources	Parents, physicians, staff from local agencies
Year Established	1974
Guiding Legislation	Individuals with Disabilities Education Act (IDEA) Part B – Assistance for Education of All Children with Disabilities
Eligibility Criteria	**Age:** 2 through 21 **Diagnostic:** any disability **Functional:** disability impacts ability to receive an appropriate education **Financial:** none
Cost of Services	No cost to families. Schools are required to provide a free and appropriate education (FAPE.)

Program Funding ($M)	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Federal	$256	$255	$243	$225
State	472	428	423	377
Local	1,297	1,188	1,005	1,025
TOTAL	**$2,024**	**$1,871**	**$1,670**	**$1,627**

Individuals Served	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Total	**169,538**	**172,631**	**175,730**	**175,579**
With ASDs	7,580	6,449	5,674	4,751

Comprehensive Services Act for At-Risk Youth and Families

Program Description	Provide comprehensive services that are child-centered, community-based, cost-effective, and family-focused to at-risk children and youth
State Administrative Agency	Office of Comprehensive Services, which is overseen by the State Executive Council (SEC). The State and Local Advisory Team (SLAT) manages the cooperative efforts among the various State agencies involved and is an advisory body to the SEC.
Local Administration	Local CSA programs receive policy guidance and management from Community Policy and Management Teams (CPMT); Family Assessment and Planning Teams (FAPT) determine eligibility and develop service plans
Service Providers	Local CSA programs contract with local private or nonprofit service providers
Referral Sources	Local DSS offices, schools, other local agencies, and families
Year Established	1992
Guiding Legislation	*Code of Virginia*, Title 2.2 Chapter 52
Eligibility Criteria	**Age:** 0-21 **Diagnostic:** none **Functional:** serious emotional and behavioral problems **Financial:** none **Other:** Entitlement for children in foster care, at risk of being placed in foster care (foster care prevention), or receiving special education services in a private placement because their needs cannot be met in the public school setting; subject to funding availability for others.
Cost of Services	No cost to families

Program Funding ($M)	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Federal	**-**	**-**	**-**	**-**
State	$244.3	$219.6	$189.2	$174.2
Local	136.2	122.7	105.9	99
Other	-	-	-	-
TOTAL	**$380.5**	**$342.2**	**$295**	**$273.2**

Individuals Served	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Total	**18,195**	**18,458**	**17,109**	**16,247**
With ASDs	831	687	605	518

Vocational Rehabilitation

Program Description	Provides job coaching and supported employment services to assist individuals with disabilities to find and maintain competitive employment.
State Administrative Agency	Department of Rehabilitative Services
Local Administration	42 field offices and more than 80 private employment services organizations
Service Providers	DRS field offices and private employment services organizations
Referral Sources	Schools, local departments of social services
Year Established	1920
Guiding Legislation	Federal Vocational Rehabilitation Act and State Law
Eligibility Criteria	**Age:** none **Diagnostic:** any disability **Functional:** limited ability in multiple domains **Financial:** none
Cost of Services	Some financial participation required.

Program Funding	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Federal	$58.35	$56.84	$55.56	$47.88
State	14.42	13.87	14.29	13.61
Local	-	-	-	-
Other	-	-	-	-
TOTAL	**$72.77**[a]	**$70.71**	**$69.85**	**$61.48**

Individuals Served	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Total	**25,105**	**24,933**	**24,563**	**23,409**
With ASD	794	652	489	372

[a] Includes State funding for the long-term employment support services.

Woodrow Wilson Rehabilitation Center

Program Description	Provides campus-based vocational and life skills training to transition-age school students and to adults with disabilities to provide them with the skills needed to find and maintain competitive employment
State Administrative Agency	Department of Rehabilitative Services
Local Administration	None
Service Providers	WWRC is sole service provider
Referral Sources	Schools and DRS
Year Established	1947
Guiding Legislation	Federal Vocational Rehabilitation Act and State Law
Eligibility Criteria	**Age:** 18 or older, unless for programs designed for minors **Diagnostic:** all disabilities **Functional:** Must be medically, physically, and psychologically stable and have a favorable prognosis to complete and benefit from services **Financial:** none
Cost of Services	May require financial participation.

Program Funding	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Federal	$13.66	$12.67	$13.63	$11.72
State	9.13	10.36	9.72	9.02
Local	-	-	-	-
Other	1.67	2.34	2.24	1.94
TOTAL	**$24.47**	**$25.36**	**$25.59**	**$22.67**

Individuals Served	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Total	**2484**	**2447**	**2605**	**2424**
With ASDs	123	86	76	45

Centers for Independent Living

Program Description	Independent non-profit agencies that provide services and advocacy to promote the independence of people with disabilities. Services include information and referral, advocacy, peer counseling, and independent living skills training.
State Administrative Agency	Department of Rehabilitative Services
Local Administration	16 separately governed CILs
Service Providers	CIL staff, community-based providers, Medicaid waiver providers
Referral Sources	Schools, DRS, and DSS
Year Established	1985
Guiding Legislation	Parts B and C, Title VII of the Federal Rehabilitation Act
Eligibility Criteria	Services available to individuals with significant disabilities, but more specific criteria vary by individual CIL
Cost of Services	No cost to clients

Program Funding	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Federal	$1.50	$1.54	$1.55	$1.55
State	5.24	5.14	4.82	4.44
Local	1.00	n/a	n/a	n/a
Other	-	-	-	-
TOTAL	**$7.74**	**$6.68**	**$6.36**	**$5.99**

Individuals Served	**SFY 08**	**SFY 07**	**SFY 06**	**SFY 05**
Total	**8,500+**	**8,600+**	**n/a**	**n/a**
With ASDs	453	n/a	n/a	n/a

Appendix E

Rating of Virginia's Early Intervention Programs

Table E-1 describes components of effective early intervention programs for young children with ASDs.

Table E-1: Effective Early Intervention Programs for Young Children With ASDs Contain Several Key Components

Component	Description
Family involvement	Programs should encourage family involvement in planning and implementing interventions as they have unique insights into the needs of their children and provide an opportunity for interventions to continue in the home.
Individualization of services	Goals, intervention strategies, and assessment criteria should be individualized for each child. Decisions should be made based on the child's needs and abilities and the family's concerns, priorities, and resources.
Intensity of intervention	Children should be actively participating in social and nonsocial environments for at least five days a week over the course of two to three years, and for at least 20 to 25 hours per week for children age three and older. Interventions may occur within a program, home, or community setting.
Interventions at early ages	Program eligibility should be designed so that children have the ability to begin interventions as soon as they are identified as having an ASD, developmental delay, or atypical development.
Specialized curriculum (ASD-specific)	Programs should be designed to address deficits in skills children with ASDs often experience: paying attention to their environment, imitating others, comprehending and using language, playing appropriately with toys, and interacting socially with others. In addition, programs should use interventions that are developmentally sequenced and have a functional approach to problem or challenging behaviors.
Structured environment	Interventions should be predictable and follow routines. The environment should be structured to minimize distractions, and the child-to-staff ratio should be low to facilitate the acquisition of specific skills. As skills are acquired, high levels of support should fade and the environment becomes more natural to aid in generalization of skills.
Systematic instruction	Instruction should be based on a conceptual or theoretical framework for teaching children with ASDs; designed to achieve meaningful goals; and logically planned, consistently implemented, and adjusted based on data pertaining to child progress.

Source: JLARC staff review of the literature assessing the components of effective early intervention programs for young children with ASDs.

JLARC staff considered three factors in determining the extent to which Virginia's early intervention programs (Figures E-1 and E-2) implemented these key components with respect to serving young Virginians with ASDs: (1) whether the program is required by federal or State laws or regulations to implement the component, (2) statements by State and local program staff regarding the extent to which components are implemented in practice, and (3) results of staff surveys which provided information as to whether efforts to address these components are having the desired impact for young children with ASDs.

Figure E-1: Explanation for Staff Ratings of the Part C Program Related to Serving Infants and Toddlers With ASDs

	Component	Implementation	Explanation
Effective Early Intervention Programs For Young Children with ASDs	Family Involvement	●	• Part C of IDEA requires families to participate in the service planning process • Local Part C program staff in all eight areas emphasized that parents and other caregivers are coached by service providers to provide the interventions
	Individualization of services	●	• Local Part C program staff in all eight areas stressed that service plans (Individualized Family Service Plan or IFSP) are developed for each infant or toddler based on his or her unique needs, as required by Part C of IDEA
	Intensity of intervention	○	• Part C of IDEA requires that the number of hours, frequency, and duration of services must be provided as listed in IFSP • Most children only receive 1-2 hours of services per week from Part C providers; Provision of additional hours is responsibility of parents and other caregivers
	Interventions at early ages	🔵	• Serves eligible children from birth through age two, as required by Part C of IDEA • ASD diagnosis is not required – children are eligible if have developmental or atypical delay • Many children with ASDs do not receive Part C services according to staff surveys
	Specialized curriculum	🔵	• Part C of IDEA states that services should address each child's needs in the areas of physical, congitive, communication, social, emotional, or adaptive development • A sizable proportion of caregivers rated the impact of Part C services on their child's functional needs as poor
	Structured environment	○	• Part C of IDEA requires services to be provided in natural environments to the maximum extent appropriate • Children typically receive services in their own home or in a day care setting with typically developing peers • Burden of structuring the environment is placed on the family or other caregivers
	Systematic instruction	🔵	• Part C of IDEA requires services and goals listed in the IFSP to be based on comprehensive assessments; IFSPs must be reviewed at least annually, but more frequently if the need arises • Lack of training in ASDs (as cited by local Part C program staff) can impact the quality of service planning
General Effective Program Practices	Research-Based Interventions	🔵	• Part C of IDEA requires provision of research-based practices • Few Part C programs provide research-based practices such as ABA-based therapies
	Qualified Personnel	🔵	• Service providers will be required to complete training modules to become Part C providers as of July 1, 2009; trainings do not focus on ASDs and Part C providers are not required to participate in other ASD-specific trainings • Communities of Practice in Autism (COPA) groups were formed in 2008 to address knowledge and training for providers working with children with ASDs; Groups are regional so information and trainings provided may not be consistent statewide • Training offered by Virginia Autism Council (VAC) historically has not focused on serving infants and toddlers but new modules for this population were recently developed
	Outcome measurement	🔵	• Individual child progress is measured based on ability to meet goals listed in IFSP • Part C of IDEA now requires states to report child outcome measures, but no requirement to report them by disability; no Virginia-specific requirement to report outcomes by disability

Legend

In terms of its benefit to young children with ASDs, this component is

● Strong - emphasized by program and generally implemented

🔵 Inconsistent – emphasized by program but not always implemented

○ Weak – not emphasized by program and generally not implemented

Source: JLARC staff review of federal and State program documents, discussions with State and local program staff, and analysis of survey results.

Figure E-2: Explanation for Staff Ratings of School Part B Services for Preschool-Age Students With ASDs

	Component	Implementation	Explanation
Effective Early Intervention Programs For Young Children with ASDs	Family Involvement	○	• Part B of IDEA requires families to participate in service planning • Schools can provide support and training to families, but they reported limited resources are available for this purpose • Thirty percent of caregivers surveyed reported receiving training to reinforce school services
	Individualization of services	●	• Special education staff in all eight regions stressed that service plans (Individualized Education Program or IEP) is developed for each student based on his or her unique needs
	Intensity of intervention	○	• Part B of IDEA requires that the number of hours, frequency, and duration of services must be provided as listed in the IEP • Thirty percent of caregivers reported preschool-age child received appropriate intensity of services to meet his or her needs
	Interventions at early ages	●	• Eligible children as a young as age 2 on September 30 of the school year can receive special education services, according to Virginia regulations • Medical or educational ASD diagnosis is not required – children are eligible if meet school's definition of developmental delay
	Specialized curriculum	◍	• Part B of IDEA states schools must consider the academic, developmental, functional, behavioral, and communication needs of students receiving special education and related services • Parents reported that schools not adequately addressing ASD-related needs of preschool-age children
	Structured environment	◍	• Part B of IDEA requires schools to provide students with those services listed in their IEP, and preschool programs are one option for young children • Most elementary schools surveyed offer preschool classes, including classes for students with developmental disabilities and/or ASDs so opportunities for structured environments exist • Few preschool-age students with ASDs receive 1:1 instruction
	Systematic instruction	◍	• Part B of IDEA requires services and goals listed in the IEP to be based on comprehensive assessments; IEPs must be reviewed at least annually, but more frequently if the need arises • Lack of training and expertise in ASDs as indicated in staff survey can impact the quality of service planning
General Effective Program Practices	Research-Based Interventions	◍	• Part B of IDEA requires provision of research-based practices • Eighty-one percent of schools with preschool programs reported using scientifically based practices though this varied by region; half reported using practices that are not recommended
	Qualified Personnel	◍	• Part B of IDEA requires that schools use highly qualified staff • Over half of caregivers reported school staff (teachers, aides, and related services) had necessary experience to address ASD-related needs of their children • Over half of schools with preschool classes that were surveyed reported lack of teachers certified in ASD interventions was moderate or significant challenge to meeting student's needs
	Outcome measurement	◍	• Individual child progress is measured based on ability to meet goals listed in IEP • Part B of IDEA now requires states to report child outcome measures, but no requirement to report them by disability; no Virginia-specific requirement to report outcomes by disability

Legend

In terms of its benefit to young children with ASDs, this component is

● Strong - emphasized by program and generally implemented

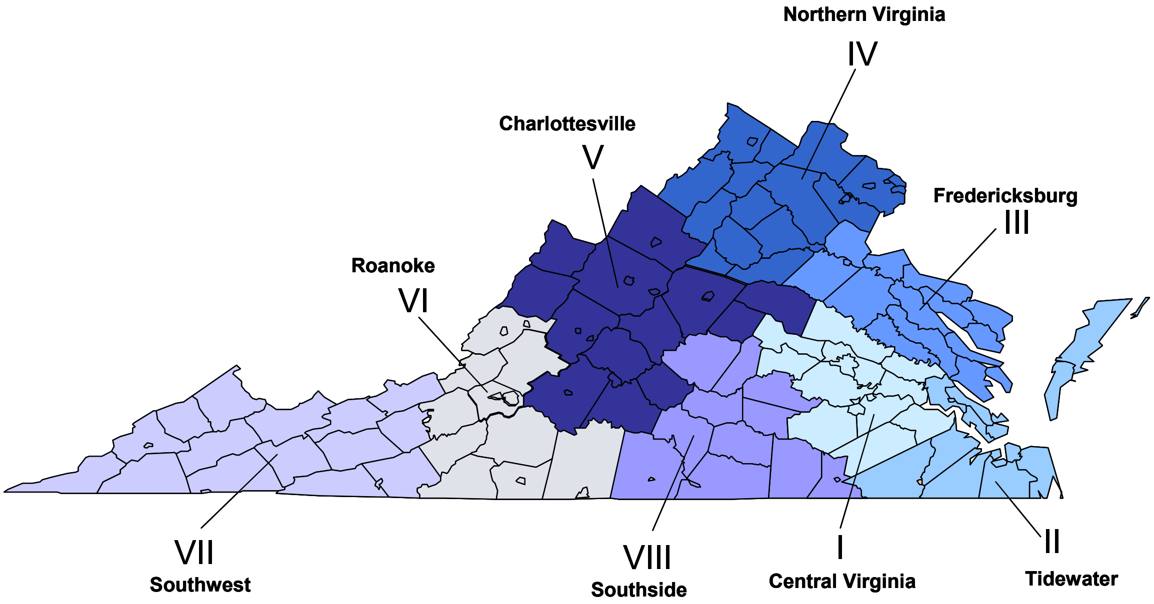
◍ Inconsistent – emphasized by program but not always implemented

○ Weak – not emphasized by program and generally not implemented

Source: JLARC staff review of federal and State program documents, discussions with State and local program staff, and analysis of survey results.

Appendix **F**

Virginia Department of Education's Superintendent's Regions



Source: Virginia Department of Education.

COMMONWEALTH of VIRGINIA

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May 29, 2009

Mr. Philip A. Leone, Director
Joint Legislative Audit and Review Commission
Suite 1100, General Assembly Building, Capitol Square
Richmond, Virginia 23219

Dear Mr. Leone:

Thank you for the opportunity to comment on the exposure draft report, "Assessment of Services for Virginians with Autism Spectrum Disorders." The Department of Mental Health, Mental Retardation and Substance Abuse Services recognizes the significant needs of the people with autism spectrum disorders and their families and the complexities of serving these individuals.

The Department supports JLARC's recommendations to develop a more coordinated and integrated system to support individuals and families with autism spectrum disorders in the Commonwealth.

The 2009 General Assembly provided funding to the Department to recruit two specialists in autism spectrum disorders and developmental disabilities. These two individuals, who will begin work in the summer of 2009, will move forward with establishing a plan to improve coordination among state agencies serving individuals with autism spectrum disorders, identify service gaps and resources needed at the local and regional level to serve individuals, improve information and outreach to families, and improve training and workforce skills for people who serve individuals with autism spectrum disorders. JLARC's recommendations support this work and underscore the importance of outreach, education, and coordination of services and policies for individuals with autism.

We are committed to working with stakeholders during the planning process and partnering with community services boards to identify adequate funding, training, and resources needed to potentially act as regional providers.

On July 1, the Department will change its name to the Department of Behavioral Health and Developmental Services, this name change reflects our vision for the agency as one that serves as a resource for all people with developmental disabilities, including those with intellectual disabilities and those with autism spectrum disorders.

We are committed to moving forward as the coordinating entity for autism in the Commonwealth and we look forward to working with you and your staff to utilize the information and recommendations in the report to move forward.

Sincerely,

James Reinhard

James S. Reinhard, M.D.

COMMONWEALTH of VIRGINIA

Patricia I. Wright, Ed.D.
Superintendent of Public Instruction

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May 28, 2009

Mr. Philip A. Leone
Director
Joint Legislative Audit and Review Commission
General Assembly Building, Suite 100
Richmond, Virginia 23219

Dear Mr. Leone:

Thank you for giving the Virginia Department of Education the opportunity to comment on the Exposure Draft of *Assessment of Services for Virginians with Autism Spectrum Disorders*. JLARC has worked with agencies, organizations, school personnel, and other individuals to gather information about services and supports for individuals with autism spectrum disorders (ASD). While the recommendations and options suggest a wide variety of considerations to improve and enhance efforts in Virginia, they also raise some concerns from the Department's perspective. The concerns relate directly to the following portions of the exposure draft as italicized.

1. The treatment of applied behavioral analysis (ABA)

   Packages such as ABA, LEAP or TEACCH prescribe a curriculum (p.16) and *schools report using comprehensive packages such as applied behavioral analysis* (p. 114).

   ABA is not a curriculum or a comprehensive package. It is "the specific and comprehensive use of principles of learning, including operant and respondent learning, in order to address behavioral needs of widely varying individuals in diverse settings."[1] ABA includes a large number of techniques, such as analysis and measurement, assessment, developing an individualized curriculum, use of

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[1] The Behavior Analysis Certification Board http://www.bacb.com/becom_frame.html retrieved 5/24/09.

reinforcers, promoting generalization and decreasing behaviors, that can be used in various combinations across many different contexts[2].

Several treatment approaches have been found to meaningfully improve the outcomes if individuals with ASDs, including the commonly referenced applied behavioral analysis (ABA) method. (p.ii) See also p.11, p.79.

The document mentions research-based practice and lists only ABA as an example. The principles of ABA are used in methods such as Activity Schedules, Behavior Chaining, Discrete Trial Instruction, Errorless Learning/Teaching, Incidental Teaching, Peer-Mediated Social Skills Training, Positive Behavior Support (PBS), Shaping, and Verbal Behavior. These interventions use specific principles of ABA and are designed based on the individual needs and behaviors of the learner. Research-based practices such as Pivotal Response Training, Picture Exchange Communication System (PECS), Verbal Behavior, Social Communication Emotional Regulation Transactional Support (SCERTS), and Social Stories could also be included as examples of research-based practices.

The Autism Special Interest Group (SIG) of the Association for Behavior Analysis states that "professional certification in behavior analysis is evidence that a professional has met minimum competency standards related to the practice of behavior analysis; however, **it does not guarantee that the individual has specific expertise in the treatment of autism** nor that s/he has the skills needed to produce optimal treatment outcomes." [3] (emphasis added in the original)

2. Application of the Mandates Under the Individuals with Disabilities Education Act (IDEA) and Virginia Regulations Governing Special Education Programs for Children with Disabilities

   A. Suggestion that decisions for special education and related services can be made by those other than the student's Individualized Education Program (IEP) team

> *The School Part B programs serving children ages two to five do not emphasize family involvement. Neither of these two programs emphasizes providing intensive services* (p.v). See also p.77.

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[2] Anderson, S. Romanczyk, R, (1999) Early Intervention for Young Children with Autism: Continuum-Based Behavioral Models, JASH 24,3, p 162-173.

[3] Consumer Guidelines for Identifying, Selecting, and Evaluating Behavior Analysts Working with Individuals with Autism Spectrum Disorders http://www.abainternational.org/Special_Interests/AutGuidelines.pdf p. 3 retrieved 5/24/09.

Family involvement and interventions are determined by the child's IEP team in accordance with state and federal regulations governing special education, not by the Virginia Department of Education (VDOE) staff.

Even when conducting on-site consultations, T/TAC personnel interviewed by JLARC staff reported that their role is not to act as the school's expert for determining how best to serve an individual student (p.118).

While TTAC staff are a valuable resource, they do not serve on the IEP team and cannot take the place of the IEP team's determinations for individual students. Considerations are provided to the IEP team that is responsible for developing an IEP that includes "a statement of the special education and related services and supplementary aids and services to be provided for the child, or on behalf of the child, and a statement of the modifications or supports for schools' personnel that will be provided for the child" (34 CFR §300.347 (a) (3)).

B. *While Virginia schools report generally being able to provide an appropriate education to children with ASDs, it appears that most struggle to fully meet these students' multifaceted needs and prepare them for independent living* (p.vi). *This has been commonly interpreted to mean that schools are not expected to provide students with disabilities the best of all possible educations…A 2006 U.S. District court case, K.L. v. Mercer Island School District found that "providing a meaningful educational benefit under the IDEA requires programs and results which reflect the Act's emphasis on preparation for self-sufficiency* (p.109).

Virginia is in the Fourth Circuit and therefore holds to the *Rowley* standard.

C. *Prior to accessing services, the possibility of an ASD must first be identified and subsequently confirmed through a diagnosis* (p.27). *One potential venue for a regional multidisciplinary diagnostic team would be local school districts, because schools are already involved in making educational diagnoses* (p.67).

A medical diagnosis is not a requirement for identification as a child with a disability who needs special education and related services. The regional team does not make diagnoses, but completes assessments that can be considered by the local school division's eligibility team.

D. *Currently, SOQ staffing ratios for pre-school classrooms containing children with ASDs are staffed at 6:1 (child:staff) or 8:1, but these ratios neither account for the age of the student nor the severity of the ASD symptoms* (p.94).

The Virginia regulations governing special education define the caseload maximum for Autism as 8:2 (with paraprofessional) and 6:1 (without paraprofessional). Preschool-aged center-based programs are required to have 8 children to 2 adults (one teacher and one paraprofessional). School divisions are permitted to employ additional staff using local funds. Individualized instruction or assistance can also be included in the IEP if required to provide a free and appropriate public education.

3. Provision of professional development and guidance by VDOE and TTAC

A. *Furthermore, though DOE and its Training and Technical Assistance Center (T/TAC) staff promote the use of research-based practices, DOE has provided limited guidance about effective interventions* (p.84). See also p.115.

These statements do not reference VDOE, Autism Priority Project, and regional TTAC efforts such as:

- Presentations at statewide and regional conferences including Commonwealth Autism Services, Speech-Language Hearing Association of Virginia, Transition Forum, VDOE Hearing Officers Training, Virginia School Board Association *Autism Hot Topic* Conference Fall 2008, Virginia,
- Statewide regional training sessions on the VAC autism skill competencies and strategies,
- Development of online resources for ASD match to VAC skill competencies document,
- Autism Specialists Network Meetings (twice/year) and statewide provision of meeting materials on CD in train-the-trainer format [topics included Data Collection and Autism Training Supports in Virginia (2007), Evidenced-Based Practices, Data & Research in Autism (2008), and IEP Development and Data Use (2009)], and
- Development of VDOE guidelines for Autism (expected publication and training in late fall 2009).

B. *The agency has not provided guidance on best practice techniques for developing IEPs specifically for students with ASDs. Moreover, DOE has not emphasized the importance of tracking students' progress by frequently recording quantifiable data for students with ASDs* (p. 122). See also p.132.

These statements do not include information on the following activities:

- Development of 16 autism specific Web shops (www.ttaconline.org);
- Host 2 annual Autism specific TTAC conferences: Virginal Tech and VCU Insight;
- Publish Autism E news (30+ issues 2004-2009) 1,700+ subscribers;
- Ongoing support for Autism Train-the-Trainer teams (20 teams) with ASD materials and tools to use for consultation and training. From September 2008 to March 2009 these teams provided 459 events reaching 3,919 individuals across Virginia;

- Support and funding for Communities of Practice in Autism with early intervention and Part C;
- Development of Data CD by ODU TTAC (including sections on data collection, analysis, and forms for teacher use);
- Annual Autism Specialists Network focus on data including tutorials for aim and trend line graphing and data collection tools and comprehensive IEP development;
- Support for and collaboration with autism organizations including Commonwealth Autism Services, Shenandoah Valley Autism Project, Autism Society of America local chapters, and Virginia Institute of Autism; and
- Provide the majority of funding of the Virginia Autism Council which developed the skill competencies[4] and strategies training.

C. *JLARC staff found that only one T/TAC staff person across all seven T/TACs is professionally certified in an intervention that is considered effective for students with ASDs* (p.118).

TTAC staff have certification in interventions that are considered effective including: Picture Exchange Communication System (PECS), Social Communication Emotional Regulation Transactional Support (SCERTS) Level I and II, Teaching and Education of Autistic and related Communication-handicapped Children (TEACCH) Level I and II, and BCBA® and training in numerous additional interventions such as Positive Behavioral Supports, Social Stories, and Visualizing and Verbalizing that do not offer an official certification.

4. Technical Corrections and Comments

In addition, families of children with ASDs can obtain information about the special education system through parent resource centers available in every school division (p.31).

There are currently 48 PRCs that serve 53 of Virginia's 132 school divisions. The Parent Education and Advocacy Training Center (PEATC), Virginia's federally funded parent information and advocacy service, provides support throughout Virginia.

The Advisory Consortium on Intellectual and Developmental Disabilities (TACIDD) could become formalized through the Code of Virginia and report on

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[4] Skill Competencies for Professionals and Paraprofessionals in Virginia Supporting Individuals with Autism Across the Lifespan, Virginia Autism Council, 2005 **www.autismtrainingva.org** .

its progress annually. Membership of this workgroup could include individuals with ASDs, caregivers, and advocates; providers; decision-makers from all agencies that serve individuals with ASDs and their families; and staff from BHDS (p. 44).

Citing The Advisory Consortium on Intellectual and Developmental Disabilities (TACIDD) as the group to be formalized to serve in this capacity does not recognize the expertise and efforts of the Virginia Autism Council (VAC). The VAC has current and historical information about autism in Virginia and includes parents, private providers, and stakeholders from across Virginia.

Evidence suggests that ASD diagnoses are occurring later in Virginia...Data from Virginia public schools show that the number of children with an ASD diagnosis peaks at age nine (p.53-54).

Currently there is no statewide system to track diagnosis of autism. The VDOE child count data that is referenced is only a measure of the educational identification or category that is agreed to by the parents and school division and reported to the VDOE annually. Children with ASD under the age of 8 may be identified as Developmentally Delayed. Virginia regulations state that "Nothing in this chapter requires that children be identified by their disability, as long as each child has a disability under this chapter and by reason of that disability needs special education and related services." (8 VAC 20-80-56 H).

Among students with ASDs who have been receiving special education services for at least a year, 73 percent of students require the same or greater level of services than when services were first initiated by the school. (p.111). *While research on interventions for children with ASDs indicates that many children who receive appropriate services will require fewer special education services and supports over time, this does not occur for most Virginia students with ASDs* (p.110).

The text states that students receiving appropriate services will require fewer special education services and supports over time. Level of services cannot be used to determine appropriateness of services. Virginia regulations governing special education require parental consent prior to "any revision to the child's IEP services." 8 VAC 20-80-70 E. 1. c. A parent may refuse to decrease IEP services even when a child has made progress and no longer requires the same level of intervention.

According to DOE staff, the foremost objective of the Priority Project is to determine the degree of effectiveness for the various interventions and strategies that have been promoted for students with ASDs (p.115).

This is not the objective of the project. The Autism Priority Project serves to build capacity for local school divisions, provide statewide high quality professional development, technical assistance, collaborate with other organizations and groups working with children with ASD in Virginia.

Most significantly, in 2006 VAC initiated an ASD certificate program which is offered to both existing and future teachers in seven Virginia colleges and universities (p.120).

The VAC created an incentive program to recognize college and university training programs that cover 80 percent or more of the knowledge and skill competencies in a sequence of courses leading to a certificate in autism. Educators in recognized programs are eligible for tuition reimbursement from the VAC. The VAC does not offer any college coursework or grant certificates in autism.

Currently, DOE dedicates half a staff position to the role of State autism specialist (p. 125) -- this should be a .33 FTE position.

DOE could undertake an assessment of teacher's ASD competencies. The professional development tracking tool that was recently developed for school personnel to compare their own ASD knowledge to the VAC's skills competencies could be used by school divisions to collect this information (p.131)

This statement requires clarification. The PD tracker was designed to assist educators in documenting training in ASD and identifying areas for additional study. The items in the PD tracker are based on the knowledge and skill statements from the VAC skill competencies and not designed to be used as a formal assessment of autism knowledge.

Thank you for the opportunity to review the Exposure draft and submit feedback. I hope this information is useful to you as you finalize this document.

Sincerely,

Pat I. Wright

Patricia I. Wright, Ed.D.
Superintendent of Public Instruction

PIW/DC/MI

COMMONWEALTH of VIRGINIA

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May 29, 2009

Philip A. Leone
Director
Joint Legislative Audit and Review Commission
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Capitol Square
Richmond, Virginia 23219

Dear Mr. Leone,

This letter is in response to the draft report Assessment of Services for Virginians with Autism Spectrum Disorders, received by my office on May 21, 2009. This report represents a significant synthesis of complex information, and I commend the Commission's staff for producing a clear summary of services available in the Commonwealth. I offer the following brief technical corrections:

- Page 23 paragraph 1 – "The Department of Health operates eight child development clinics…" Please change this to "nine" clinics.

- Page 25 Table 6 – "Funding Sources listed for Child Development Clinics" is listed as "84% Federal and 16% Other". Our fiscal records indicate that for FY08, funding for the Clinics was 46% General Funds and 54% Federal Funds (see the detail presented below regarding Appendix D).

- Page 66 Table 14 – "Disadvantages" column related to Child Development Clinics – "Requires recruiting speech and occupational therapists" and "Is limited to 8 locations". We do not believe that speech and occupational therapists would be needed to diagnose children with Autism Spectrum Disorders. The number of clinics again needs to be changed to 9.

- Page 68 Paragraph 1 – We feel the last sentence is not really accurate. The CDCs report increased referrals for evaluation of children suspected of having autism spectrum disorders. While the clinics do not have speech or occupational therapy specialists available, several have staff trained specifically in assessment instruments used for diagnosing autism. Two clinics have developmental pediatricians on staff who are qualified to diagnose autism.

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- Appendix D Page D-1 – Please change as follows:
    - Program Description: The Clinics also conduct screening for the Developmental Disability Waiver
    - Local Administration: State universities also house Clinics
    - Service Providers: The educational consultant is actually employed by a local school division
    - Referral Sources: The second highest referral source is local departments of social services
    - Eligibility Criteria…Diagnostic: Children may be referred if they are suspected of or at risk of developmental disability or behavioral disorder

The Program Funding Table on Page D-1 contains information that was provided by our staff as an estimate. We have since obtained the specific information from our fiscal files as follows:

Funds ($M)	SFY 08	SFY 07	SFY 06	SFY 05
Federal	$1.92	$2.02	$1.78	$1.85
State	1.63	1.61	1.54	1.59
Local				
Other	0.01	0.01	0.20	0.15
Total	$3.56	$3.63	$3.52	$3.59

I appreciate the opportunity to offer these clarifications to your Commission's draft report. Please do not hesitate to let me know if you have questions about these comments. The Virginia Department of Health staff and I look forward to the discussion that will take place at the June Commission meeting.

Sincerely,

Karen Remley

Karen Remley, MD, MBA, FAAP
State Health Commissioner

cc: The Honorable Marilyn Tavenner

COMMONWEALTH of VIRGINIA

Department of Medical Assistance Services

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May 29, 2009

Mr. Philip A. Leone
Director
Joint Legislative Audit and Review Commission
Suite 1100, General Assembly Building, Capital Square
Richmond, VA 23219

Dear Mr. Leone:

Thank you for the opportunity to review and comment on the exposure draft of the report titled *Assessment of Services for Virginians with Autism Spectrum Disorders*. I commend you and your staff's effort in its extremely broad examination of a very complex set of issues facing the Commonwealth. We greatly appreciate the collaborative nature of your staff's approach to researching and reporting on autism services.

In the time allowed for our review, we have not attempted to verify every Medicaid-related statistic presented in the report, as we understand these data were primarily derived from information requested from and provided by my staff at the Department of Medical Assistance Services (DMAS). Overall, we have no dispute with the facts regarding Medicaid coverage (or options for coverage) as presented in the draft report. Your staff has done an excellent job summarizing the complexity of eligibility for and coverage of autism-related services under Medicaid.

Regarding the Medicaid-specific recommendations, I offer the following comments:

Recommendation 4: The Department of Medical Assistance Services should develop and implement a plan for educating Virginians with autism spectrum disorders (ASDs) and their families; Medicaid case managers; providers; and personnel from relevant programs including School Part B, Early Intervention Part C, and Comprehensive Services Act about the availability of Medicaid waivers and programs through which needed services can be obtained. In particular, outreach efforts should convey that individuals with ASDs may be eligible for the Elderly or Disabled with Consumer Direction waiver, and that Medicaid and waiver recipients under age 21 can receive a comprehensive array of medically necessary services through the Early and Periodic Screening, Diagnosis, and Treatment program. The

department should report on its outreach efforts to the Joint Commission on Health Care no later than November 30, 2009.

The Department has no objection to the intent of this recommendation and certainly concurs that existing outreach efforts to promote a better understanding of our waiver programs and coverage available under the Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT) should be continued and enhanced with specific information related to individuals with ASDs. As always, we are more than willing to brief the Joint Commission on Health Care (JCHC) on any issues pertaining to Medicaid and the other programs administered at DMAS at their request and according to their needs and schedule. It is not clear in the recommendation if there is an expectation that outreach efforts should be *completed* in order to meet a November 30, 2009 reporting deadline; if this is intended, it may not be practical for either DMAS (due to the breadth of the recommended outreach) or the JCHC (due to their current meeting schedule and work plan) to meet that deadline. Obviously, DMAS would defer to the JCHC regarding their desire for a status update on outreach efforts under the timeline proposed by this recommendation.

Underlying this recommendation is the notion that available autism-related services in the Medicaid program are underutilized based on a lack of knowledge regarding eligibility for Medicaid waivers, particularly the Elderly and Disabled with Consumer Direction (EDCD) waiver, which currently has no cap on enrollment, and the resulting access to both waiver services (for all ages) and services available under EPSDT (for recipients under age 21). As noted in the JLARC report, a broader understanding that these services are available to those eligible under Medicaid (through the enhanced outreach effort described in the recommendation) should certainly improve access to needed autism-related services. However, the EDCD waiver is unlikely to be the panacea for the entire population, as recipients would still need to meet the eligibility requirements (both medical and functional) of the waivers; many individuals may not meet those criteria.

Secondly, and again pointed out by the JLARC report but reiterated here, any increase in utilization of services under Medicaid will have a fiscal impact on the Commonwealth (albeit with the federal government funding a significant portion). I do not state this in a judgmental manner, but rather as a pragmatic recognition of the current budget environment in the Commonwealth of Virginia. As always, the Governor and General Assembly will determine the funding priorities of the Commonwealth, and the Department will react accordingly.

Recommendation 7: The Department of Medical Assistance Services should collaborate with relevant stakeholders to (1) evaluate the options for enhancing the early intervention system by improving the Medicaid programs serving young children with autism spectrum disorders; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

Recommendation 12: The Department of Medical Assistance Services should collaborate with relevant stakeholders to (1) evaluate the options for improving the delivery of services to school-age children with autism spectrum disorders by increasing knowledge about Medicaid services, developing standards and rates for Medicaid providers, and adjusting existing or creating new waiver programs; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

Recommendation 16: The Department of Medical Assistance Services should collaborate with relevant stakeholders to (1) evaluate the options for fostering greater independence among adults with autism spectrum disorders by improving Medicaid waiver programs; (2) identify which, if any, options are most beneficial to pursue; and (3) report its findings to the Department of Behavioral Health and Developmental Services no later than March 31, 2010.

These three recommendations follow a common theme, and the evaluation component of these recommendations is already underway as part of the Department's collaboration with the Department of Behavioral Health and Developmental Services (DBHDS) in examining the feasibility of creating an Autism-specific waiver. This process has been and will continue to be an open process with active participation by the relevant stakeholders. As part of this process, services under the current waivers will be examined with an eye toward options to either modify the existing service offerings or develop a new waiver program targeted toward the specific needs of individuals with ASDs. This process is in its early stages, but on track for the development of potential options for consideration by the Governor and General Assembly in the 2010 Session. While we have no concern with the reporting deadline, DBHDS is co-chairing this effort, so a separate report from DMAS to DBHDS seems unnecessary.

DMAS stands ready to work with all interested parties to further explore whatever options the Governor and General Assembly believe appropriate in response to this report. Again, thank you for the opportunity to comment on the draft report.

Sincerely,

Patrick W. Finnerty
Director

PWF/sf

cc: The Honorable Marilyn B. Tavenner, Secretary of Health and Human Resources

COMMONWEALTH OF VIRGINIA

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June 1, 2009

Mr. Phillip A. Leone
Director
Joint Legislative Audit and Review Commissioner
Suite 1100, General Assembly Building
Richmond, Virginia 23219

Dear Mr. Leone:

Thank you for providing me with the draft report, Assessment of Services for Virginians with Autism Spectrum Disorders, prepared by the Joint Legislative Audit and Review Commission (JLARC). I have reviewed this report as it relates to the information and recommendations regarding the services at the Department of Rehabilitative Services (DRS), and I extend to you my support of the recommendations made in this report relative to DRS and my willingness to work on these efforts, recognizing the lead role of the Department of Behavioral Health and Developmental Services in service coordination for individuals with developmental disabilities.

I would like to acknowledge the excellent work of the JLARC Analysts on this report and look forward to the presentation of the report on June 8. If you need any further information, please do not hesitate to ask.

With best regards, I am

Sincerely,

James A. Rothrock

JAR/ees

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