



COMMONWEALTH of VIRGINIA

Office of the Governor

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

November 30, 2010

To: Members, Joint Commission on Health Care
Members, Joint Legislative Audit and Review Commission
Members, Senate Finance
Members, House Appropriations

In response to the directive contained in the Joint Legislative Audit and Review Commission's (JLARC) report "Assessment of Services for Virginians with Autism Spectrum Disorders" (House Document 8, 2009), I am forwarding to you a detailed action plan for addressing the needs of Virginians with developmental disabilities, including autism spectrum disorders.

House Document 8 directed that a plan be developed that reflects the input of relevant stakeholders and the evaluation of options for next steps to build a more effective system of care for this population. In response to this directive, the Department of Behavioral Health and Developmental Services (DBHDS) as lead agency worked with other state agencies to convene a number of workgroups in order to address the recommendations in the study. In addition to DBHDS, the state agencies providing leadership in this endeavor included the Department of Medical Assistance Services (DMAS), the Department of Education (DOE), the Department of Rehabilitative Services (DRS), the Department of Criminal Justice Services (DCJS), and the Department of Health (VDH). The input of the various workgroups was used to develop the detailed action plan in this report. While there was widespread participation from many interest groups for which we are very appreciative, not all stakeholder groups participated actively.

This document addresses the JLARC recommendations, describes workgroup or state agency activity to address the recommendations, and outlines specific items for future consideration or funding by the General Assembly. I am pleased to share with you that many of the recommended initiatives are already underway by our state agencies. In light of the fiscal constraints Virginia is currently experiencing, it is my recommendation that we work together over the coming year to determine which program areas that require increased funding should be considered for initial implementation.

I hope that you find the information in this report helpful in guiding Virginia's strategic efforts for individuals with developmental disabilities, including autism spectrum disorders.

Sincerely,

A handwritten signature in black ink, appearing to read "William A. Hazel, Jr.", with a stylized flourish at the end.

William A. Hazel, Jr., M.D.

Enc.

cc: The Hon. Gerard Robinson, Secretary of Education
The Hon. Marla Graff Decker, Secretary of Public Safety
Keith Hare, Deputy Secretary of Health and Human Resources
Glen S. Tittermary, JLARC Director
James W. Stewart, III, DBHDS Commissioner
Dr. Gregg A. Pane, Director, DMAS Director
Dr. Patricia I. Wright, Superintendent of Public Instruction, DOE
James Rothrock, Commissioner, DRS
Harold Clarke, Director, DCJS
Dr. Karen Remley, Commissioner, VDH
Olivia Garland, Ph.D., DBHDS Deputy Director
Heidi R. Dix, DBHDS Assistant Commissioner
Joe Flores
Susan Massart
Nathalie Molliet-Ribet
Lee Price
Ruth Anne Walker

DBHDS

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

**Response to the Joint Legislative Audit
and Review Commission Report
(House Document 8, 2009)**

***Establishing a Detailed Action Plan
for Serving Individuals with Autism
Spectrum Disorders***

November 30, 2010

Response to the JLARC Study of Services for Virginians with Autism Spectrum Disorders

TABLE OF CONTENTS

	Page
Executive Summary	3
I. Introduction	8
II. Section 1: Establishing a Coordinated System of Statewide Accountability	13
III. Section 2: Establishing a Centralized Source of Information Regarding ASDs	27
IV. Section 3: Workforce Development	30
V. Section 4: Improving Access to, Screening, Assessment, and Diagnosis of Children with ASDs	36
VI. Section 5: Enhancing Early Intervention and Treatment for Children with ASDs	44
VII. Section 6: Improving the Education System for Children and Youth with ASDs	53
VIII. Section 7: Services for Adults	58
IX. Section 8: Public Safety	69
X. Section 9: Detailed Action Plan	75
XI. Appendix A: Summary of JLARC Recommendations from <i>Assessment of Services for Virginians with Autism Spectrum Disorders</i>	85
XII. Appendix B: Glossary	88
XIII. Appendix C: Workgroups and Stakeholders	92
XIV. Appendix D: Commonwealth Autism Services Facilitated Autism Action Groups	97
XV. Appendix E: Public Comment from TACIDD Meeting	98

Executive Summary

During the past decade, the number of individuals diagnosed with Autism Spectrum Disorders (ASDs) has increased dramatically in Virginia, as well as the rest of the nation. States are exploring 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, educating and providing long-term supports for individuals with 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 concerns about the prevalence of ASDs and availability of services in Virginia, the 2008 General Assembly enacted House Joint Resolution 105 (HJR 105). This study directed 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. In addition, the mandate directed 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.

In June 2009, JLARC published House Document No. 8, “Assessment of Services for Virginians with Autism Spectrum Disorders,” in response to the General Assembly’s directive. The JLARC study contained 21 recommendations to improve services in Virginia. The JLARC recommendations in the study can be grouped into several common themes:

1. Identifying a single point of entry for access to all services in the state needed for those with a developmental disability, including ASDs, and establishing a system of statewide accountability
2. Establishing a centralized, comprehensive and reliable source of information regarding ASDs for the citizens of Virginia
3. Increasing capacity to educate and train providers of services
4. Improving access to screening and early diagnosis
5. Enhancing early intervention and treatment of children with ASDs
6. Improving educational services for children and youth with disabilities, including ASDs
7. Increasing quality of life and independence for adults with ASDs
8. Enhancing public safety for those with ASDs

The JLARC study requested in its final recommendation that:

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 response to this directive, the Department of Behavioral Health and Developmental Services (DBHDS) convened several workgroups or requested that collaborating state agencies convene workgroups to address the recommendations in the study. The input of these workgroups, which included a broad base of state agency and stakeholder involvement, was used to develop the detailed action plan in this report.

This document addresses the JLARC recommendations discussed for each theme it identified, describes workgroup or state agency activity to address the JLARC recommendations, and outlines specific items for future consideration or funding by the General Assembly. Below is a list of initial recommendations and a detailed action plan which prioritizes current and ongoing activities as well as future activities.

Recommendation #1: Adopt a single definition of developmental disabilities in Virginia.

Recommendation #2: Establish Community Services Boards (CSBs) as the single point of entry for the Developmental Disability (DD) System, including serving individuals with ASDs.

Recommendation #3: In FY12, move the day to day administration of the IFDDS waiver from the Department of Medical Assistance Services (DMAS) to DBHDS, in order to realign and increase coordination of the Intellectual Disability (ID) and Individual and Family Developmental Disabilities Waiver Services (IFDDS) waiver programs for families.

Recommendation #4: Initiate a resolution in the 2011 Virginia General Assembly to require that the Department of Medical Assistance Services, as the single state agency designated in Virginia for the Medicaid Program, and DBHDS, the administrator of the ID Waiver, convene a work group of providers of current service and relevant stakeholders to conduct a study to determine the costs and parameters of combining the ID and IFDDS Waivers into one comprehensive waiver Developmental Disability Waiver. The study will include a comprehensive review of federal requirements related to combining the current CMS approved 1915 (c) waivers and consider the differences between the two waivers renewal dates. The study should also include the impact on and recommendations related to: 1) current waiting lists; 2) existing access and enrollment processes; 3) current case management systems; 4) services offered; 5) implementation of technology; and regulatory changes needed to support a combined waiver. The recommendations should be completed by November 30, 2011 for consideration by the 2012 Regular Session of the Virginia General Assembly.

Recommendation #5: Increase grants to localities to be used by the Community Services Boards as Family and Individual Support funds as needed for individuals who are not currently receiving or are ineligible for services under the ID or IFDDS waivers.

Recommendation #6: Develop an on-line training program and expand the DBHDS-community college certificate program for direct support professionals to promote a well qualified DD community-based workforce.

Recommendation #7: Expand and develop Communities of Practice in Autism (CoPA) in order to develop skills and enhance service delivery planning/implementation through Part C Early Intervention.

Recommendation #8: Increase by 50 the number of individuals trained and certified as Positive Behavior Supports Facilitators.

Recommendation #9: Continued funding of the Virginia Autism Council through DBHDS for Council operations and tuition reimbursement for non-public education professionals and providers.

Recommendation #10: The State Infant & Toddler Connection (Part C) Program will finalize “Service Guidelines for Providing Early Intervention Services to Infants and Toddlers with ASDs,” by June 2011.

Recommendation #11: Seek grant funding to establish a statewide public service campaign regarding early detection and screening for autism.

Recommendation #12: DBHDS will work with other state agencies to increase the capacity for screening for ASDs in a non-clinical setting, such as local Departments of Social Services, day care centers, Head Start/Early Head Start and other places that come into contact with young children.

Recommendation #13: Expand existing VDH medical homes initiative to assist physicians in creating medical homes for children with autism or other special needs.

Recommendation #14: The State Infant & Toddler Connection Program (Part C) will collaborate with the Virginia Chapter of the American Academy of Pediatrics to increase pediatrician knowledge base of how and where to refer families for interdisciplinary team diagnosis.

Recommendation #15: DBHDS, DMAS and VDH will work with the VAAP and Virginia Academy of Family Physicians (VAFP) Association to increase the periodic use of regular standardized developmental screening tools for all developmental delays, including autism.

Recommendation #16: The State Part C Program should modify its data collection to track progress measures by disability, including ASDs. The State Part C Program should also collect specific disability information as part of its routine family surveys.

Recommendation #17: The State Part C Program should provide a report to the General Assembly on the cost of establishing a specialized services program to serve young children with ASDs.

Recommendation #18: The Department of Education should provide a report to the General Assembly on the costs of increasing the intensity, staffing and structure of preschool services for children with ASDs.

Recommendation #19: DBHDS should seek emergency regulatory authority to include Intensive Individual Support Services as a new license provider category.

Recommendation #20: DBHDS and DMAS should determine the level of need and associated cost of a Medicaid respite waiver to provide minimum services to children with developmental disabilities who meet waiver level of functioning criteria.

Recommendation #21: In determining appropriate strategies for addressing the treatment needs of children with ASDs, Virginia should continue to strongly consider the role of private insurance in covering treatment in the continuing effort of public/private partnership in addressing the needs of those with autism.

Recommendation #22: Promote the professional development of educators in the area of ASD expertise by creating online coursework that will result in achieving certification as a Board Certified Behavior Analyst (BCBA) or a Board Certified Assistant Behavior Analyst (BCaBA).

Recommendation #23: Expand Department of Rehabilitative Services (DRS) case services to respond to the increasing demand for ASD services.

Recommendation #24: Increase access to employment supports for up to 200 individuals through the long-term employment supports of the LTESS program.

Recommendation #25: Increase employment skills and opportunities for adults with ASDs no longer in the school system, through a dual phase Project SEARCH model.

Recommendation #26: Implement five (5) five-day, regional Autism Work Support trainings for a total of 750 participants, designed to increase the knowledge base of employment service providers, day support providers, individuals with ASDs and their family members about work supports for persons with ASDs.

Recommendation #27: Create a MicroBoard Association for Virginia to assist adults with developmental disabilities to live independently using natural supports within their home communities.

Recommendation #28: ASD Training developed by the Public Safety Workgroup should be recognized as the minimum training standard in the Commonwealth of Virginia for all public safety personnel.

Recommendation #29: All public safety personnel (including judges, magistrates,

attorneys, law enforcement, fire/EMS, etc.) should receive basic autism awareness training (developed by the PSW) to understand characteristics of autism.

Recommendation #30: The General Assembly should require all public safety personnel to receive ongoing in-service training for a more in-depth understanding and awareness of autism spectrum disorders, including current strategies and interventions to use during an encounter with an individual with autism.

Recommendation #31: The General Assembly should provide a pool of funds for public service agencies to access when they are unable to pay for ASD awareness training.

Introduction

During the past decade, the number of children with Autism Spectrum Disorders (ASDs) has increased dramatically in Virginia, as well as the rest of the nation. States are exploring 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, educating and providing long-term supports for individuals with ASDs. Furthermore, the rising prevalence of ASDs has raised questions about the ability of public safety personnel to properly respond and appropriately interact with those with ASDs when emergency and/or legal situations arise.

Description of Autism Spectrum Disorders

Autism Spectrum Disorders are a form of developmental disability that usually manifest themselves before the age of three and affect social interactions, communication and behavior. The level of impairment and manifestations of ASDs vary greatly among individuals based on their specific disorder, age and developmental level. Some individuals exhibit few or mild ASD impairments, while others may be more severely impaired. However, a number of characteristics are often shared. For example, most individuals will experience some social impairment, such as not responding to other people's smile or facial expressions, not showing concern for others or not bringing objects of interest to share with others. Individuals with ASDs often have difficulty 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 their 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. The breadth of ASD symptoms generally affects individuals' ability to function in all settings, including home, school, work and the community.

Autism Spectrum Disorders are complicated in that they often occur with other disorders. The fact that families of individuals with ASDs must learn about these medical conditions in tandem with autism further compounds the amount of stress that families experience. The most prevalent co-occurring disorders include: seizure disorders, genetic disorders, gastrointestinal disorders, sleep dysfunction, sensory integration dysfunction, pica (an eating disorder), attention deficit hyper activity disorder (ADHD), anxiety and depression.

Autism Prevalence

The Centers for Disease Control published estimates on December 19, 2009, that between 1 in 80 and 1 in 240, with an average of 1 in 110, children in the United States have an ASD. This represents a prevalence of about one percent of all children. With this current prevalence rate, the potential number of affected individuals in Virginia could range in the tens of thousands.

Currently there is no one agency collecting and maintaining data on the number of individuals in the Commonwealth with an ASD diagnosis. However, we can extrapolate possible figures from the 2009 U.S. Census Bureau numbers. Virginia's population estimate for 2009 was 7,882,590. (<http://quickfacts.census.gov/qfd/states/51000.html>). Children under age five represented 6.7% of the total population, meaning that as many as 5,281 children under the age of 5 in 2009 may have an ASD. Looking across all age ranges, one percent of the state's population equals 78,825 individuals *potentially* falling somewhere on the Autism Spectrum. Autism is currently not a reportable health condition in Virginia, so the only data available is that provided by the Virginia Department of Education (VDOE) educational category count for ages two - 22 and Part C Early Intervention medical diagnosis counts for children aged birth through three.

The Virginia Department of Education (VDOE) autism data currently is the most accurate means Virginia has in order to plan for future services for those with autism. VDOE is required by Part B of the federal Individuals with Disabilities Education Act (IDEA) to maintain data on the students that they serve with an educational label of autism. There may be an additional number of students with a medical diagnosis of autism who do not have a school-based plan for special services (an Individual Education Plan or IEP).

The number of students educationally identified with autism within the Virginia public school systems have dramatically increased in the last 12 years. In the 1998 VDOE child count, there were 1521 students enrolled within the school systems with ASDs. By 2004, that number had increased to 5179. By December 1, 2009, Child Count Data reflected 10,092 students from the ages of 0 through 22 with the primary disability category label of autism as defined by the IDEA. VDOE states that they believe this number is still an under representation of those on the Autism Spectrum, even with the dramatic increase over the last 12 years.

In an effort to better ensure that students are not inappropriately labeled, the VDOE has required a more specific disability category for the generic category of Developmental Delay. Previously, if an educational label was uncertain a child would be placed within the Developmental Delay category. Recently, the age of eligibility for Developmental Delay has changed from ages two through eight, to two through six. This change encourages local educational agencies to reassess students' abilities and performance at a younger age to determine the appropriate classification and level of services as determined by the IEP team (Virginia Department of Education, Fast Fact April 2010). There currently is no methodology available to accurately count the number of individuals with ASDs living within Virginia once they leave the public school system.

Assessing Needs in Virginia and Developing a Detailed Action Plan

In response to concerns about the prevalence of ASDs and the availability of services in Virginia, the 2008 General Assembly enacted House Joint Resolution 105 (HJR 105). This study directed 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. In addition, the mandate directed 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.

In June 2009, JLARC published House Document No. 8, “Assessment of Services for Virginians with Autism Spectrum Disorders,” in response to the General Assembly’s directive. The JLARC study contained 21 recommendations to improve services in Virginia. The 21 recommendations are outlined in Appendix A.

In an attempt to develop a detailed action plan based on JLARC’s report, several approaches were considered. The decision was made to organize the original recommendations within categories. The JLARC recommendations in the study are grouped into seven common themes:

1. Identifying a single point of entry for access to all services in the state needed for those with a developmental disability, including autism, and establishing a system of statewide accountability
2. Establishing a centralized, comprehensive and reliable source of information regarding autism for the citizens of Virginia
3. Increasing capacity to educate and train providers of services
4. Improving access to screening and early diagnosis
5. Enhancing early intervention and treatment of children with autism
6. Improving educational services for children and youth with disabilities, including autism
7. Increasing quality of life and independence for adults with autism
8. Enhancing public safety for those with autism

The JLARC study requested in its final recommendation that:

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 response to this directive, the Department of Behavioral Health and Developmental Services (DBHDS) convened several workgroups or requested that collaborating state agencies convene workgroups to address the recommendations in the study which they had state authority over. The input of these workgroups, which included a broad base of state agency and stakeholder involvement, was used to develop the detailed action plan in this report. Appendix C shows the workgroups and their participants coordinated by DBHDS. In addition, DBHDS sought public

comment on the initial draft of the action plan. Comments were sought in writing, as well as in person via a four hour public meeting of The Advisory Consortium on Intellectual and Developmental Disabilities (TACIDD). Appendix E summarizes public comments.

Comments submitted during the Public Comment period to the Department of Behavioral Health and Developmental Services covered a wide range of issues. In total 156 comments were received by BHDS. There were a large number of comments that addressed multiple areas. Specifically: Waivers, Education of Youth, and Autism Insurance Mandate. The comments are categorized by theme from the First Draft.

Summary of Public Comment Received via Email by Report Section/Theme	Comment Count
Statewide Accountability: State DD definition, Single Point of Entry, Combination of Waivers	30
Establishing a Centralized Source of Information regarding ASDs	3
Educating and Training Providers	4
Improving Access to Early Diagnosis, Screening and Treatment of Children with ASDs/ Autism Insurance Mandate	3/111
Improving the Education System for Children and Youth with ASD	21
Services for Adults: Employment and Housing	6
Public Safety: First Responders, Police, Fire, EMT	4
Miscellaneous	6
Total	188

Each section of this report will outline issues and concerns for one particular theme identified in the JLARC study, discuss recommendations from the relevant agency and workgroups, then list recommendations for the detailed action plan. This report will conclude with a detailed plan outlining the costs and implications for the implementation of these recommendations.

Section 1: Identifying a single point of entry for access to all services in the state needed for those with a developmental disability, including autism, and establishing a system of statewide accountability

Section 2: Establishing a centralized, comprehensive and reliable source of information regarding autism for the citizens of Virginia

Section 3: Increasing capacity to educate and train providers of services

Section 4: Improving access to screening and early diagnosis

Section 5: Enhancing early intervention and treatment of children with autism

Section 6: Improving educational services for children and youth with disabilities, including autism

Section 7: Increasing quality of life and independence for adults with autism

Section 8: Enhancing public safety for those with autism

Section 9: Summary of Detailed Action Plan

Section 1

Establishing a Coordinated System of Statewide Accountability

The JLARC study identified the need for a single developmental disabilities (DD) agency, improved system coordination, and improved access to care for individuals. The study also identified the need for Virginia to consider ways to improve delivery of ASD and DD services, including enhancing Medicaid waiver programs. The study concluded that a more streamlined system with greater accountability would significantly improve the ability of individuals with ASDs and their families to access services.

The lack of a lead agency designated to assume responsibility for the establishment and coordination of a DD system for Virginia was cited by the JLARC study as a major barrier to successfully resolving issues affecting individuals with ASDs and their families. The study cited the fragmentation of services that were developed by the various agencies in isolation from each other and the lack of an entity to develop a clear and unified policy direction for the Commonwealth concerning ASDs as examples of the problems that Virginians with ASDs and their families now face.

In 2009, the Joint Commission on Health Care designated DBHDS as lead agency to coordinate autism services and policy across the Commonwealth. The JLARC Study endorsed the decision for DBHDS to serve in the lead capacity by observing, "... 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..." (p. 38).

Partly in anticipation of accepting a broader role beyond the traditional role of serving individuals with intellectual disabilities, the name of the Department changed in July of 2009 from the Department of Mental Health, Mental Retardation and Substance Abuse Services to the Department of Behavioral Health and Developmental Services. Also, in October of 2009, DBHDS added two staff members to help guide and shape this new direction.

The JLARC study also noted that there is limited and fractured funding available for services for people with ASDs relative to other disability populations in Virginia (e.g., those with intellectual disabilities). As the lead agency for developmental disabilities, DBHDS began consulting with stakeholders to better define the ASD and DD population in Virginia. It is critical that a common definition of developmental disabilities, including those with ASDs be established so state agencies, including DBHDS, DMAS, VDOE, and others can appropriately plan to address the needs of this population. In addition, a common definition can assist policy officials and legislators in determining the resources necessary to serve the DD population in Virginia.

Workgroups were formed to address recommendations in the JLARC report related to the issues of the single point of entry and centralized systems management. These were made up of representatives of the Virginia Association of Community Services Boards (VACSB), Centers for Independent Living, The Arc of Virginia, DBHDS staff, DMAS Division of Long-Term Care staff, Developmental Disability Waiver case managers, family members and self-advocates.

While there was not universal consensus on all issues discussed, there was general agreement on the direction and many of the elements of changes that were recommended. The major points of agreement were:

1. DBHDS should continue to be the lead state coordinating agency for autism services and policy.
2. Virginia should adopt a definition of developmental disability to ensure appropriate services and policy development.
3. The Community Services Boards should be the single point of entry into the system for individuals with autism and developmental disabilities.
4. Individuals with autism and their families will be better served with one comprehensive developmental disability waiver rather than the current system.

Defining Developmental Disabilities for the State of Virginia

A workgroup of stakeholders convened to discuss this issue and reviewed various definitions, including the definition currently used by the federal government (Developmental Disabilities Act, section 102(8).) to define developmental disability. Another consideration was that the definition must not exclude anyone who is currently receiving state-funded services in Virginia. In the end, the workgroup defined the population by accepting the federal definition with one small change to ensure the inclusion of everyone being served currently by the Individual and Family Developmental Disabilities Waiver Services (IFDDS Waiver) which services many people with developmental disabilities, including ASDs. Those individuals whose characteristics and needs are encompassed by this definition, including those with ASDs, would qualify – with sufficient funding – for services provided by DBHDS, CSBs, and other state agencies as applicable. The proposed definition is:

"Developmental Disability" means a severe, chronic disability of an individual that

- A. *Is attributable to a mental or physical impairment or combination of mental and physical impairment;*
- B. *Is manifested before the individual attains age 22;*
- C. *Is likely to continue indefinitely;*
- D. *Results in substantial functional limitations in two or more of the following areas of major life activity:*
 - i. *self-care;*
 - ii. *receptive and expressive language;*
 - iii. *learning;*
 - iv. *mobility;*
 - v. *self-direction;*
 - vi. *capacity for independent living; and*
 - vii. *economic self-sufficiency; and*
- E. *Reflects the individual's need for a combination and sequence of special, interdisciplinary or generic services, individualized supports or other forms of*

assistance that are of lifelong or extended duration and are individually planned and coordinated.

An individual from birth to age nine, inclusive, who has substantial developmental delay or specific congenital or acquired conditions may be considered to have a developmental disability without meeting two or more of the criteria described above in (A) through (E) if the individual, without services and supports, has a high probability of meeting those criteria later in life.

Three levels of support needs were identified in this population. They are:

1. Those individuals who meet the “Level of Functioning” criteria for Medicaid services. These individuals will require the highest levels of support and will most likely require some level of support throughout their lifetime.
2. Those individuals who require a fair amount of support in order to fully integrate into the mainstream of community life, but who do not meet the “Level of Functioning” criteria that would qualify them for Medicaid services. With some supports in place to help with basic life skill needs, such as job coaching, counseling, skills training, budgeting and financial needs planning, and general periodic monitoring and companionship, these individuals can assimilate successfully into community life.
3. Those individuals who need periodic support in order to maintain an integrated lifestyle, such as case management, peer group counseling, occasional assistance with decision-making and guidance.

Designating a Single State Coordinating Agency

DBHDS, as the newly established lead, coordinating agency began working with many state and local organizations to coordinate autism services and policy. These efforts built on significant collaboration already under way.

Advocacy and Non-Profit Partners. The Advisory Consortium on Intellectual and Developmental Disabilities (TACIDD) is a workgroup of stakeholder agencies, advocates and interested parties who meet quarterly to advise the DBHDS Office of Developmental Services (ODS) on policy directions and issues of stakeholder interest. Last year, DBHDS formed the State Employment Leadership Network Advisory Group, a work group of stakeholders and agencies gathered to promote integrated employment initiatives for individuals with developmental disabilities. The Virginia Autism Council (VAC), long seen as operating under VDOE, has increasingly become a partner working more closely with the support of DBHDS. In July of 2009, state funds for the Commonwealth Autism Service (CAS) began to be channeled through DBHDS, as opposed to Virginia Commonwealth University, its former host. In doing this, DBHDS established a formal relationship with CAS. DBHDS already had a similar arrangement with the Virginia Autism Resource Center. All of these collaborative endeavors are serving to strengthen the coordination of efforts among the various agencies on behalf of individuals on the autism spectrum.

Community Services Boards (CSBs). The DBHDS contractual relationship with the forty CSBs has long been a strength of the system of ties between the Department and direct services in the community. Likewise, the relationship between the Department, the CSBs, and the more than five hundred licensed, private, community providers of services and supports provides a support network throughout Virginia for services to individuals with intellectual disabilities. Since July of last year, the CSBs have agreed that their focus should also expand in scope to include those with ASDs and other developmental disabilities. To that end, the “Intellectual Disability Council” of the VACSB has moved to change its name to the “Developmental Services Council.” Members of this council authored a white paper titled, “Shaping the Future for Comprehensive ASD Services,” in which they outlined the steps that each CSB could take now to begin to improve their responses to families and individuals with ASDs living in their communities. As the system continues to expand and broaden to accommodate the needs of individuals on the spectrum and who have other developmental disabilities, the strength of this existing network of providers and stakeholders will prove most beneficial in bringing services and supports to individuals and their families.

Department of Medical Assistance Services (DMAS). The Centers for Medicare and Medicaid Services (CMS) requires that the state Medicaid agency retain ultimate administrative authority and responsibility for the administration of all Medicaid programs, including the State Plan Option service of Targeted Case Management and all of the Waivers. While other state, local, regional or private contractual agencies may perform some of the waiver administrative functions, the state Medicaid agency must exercise oversight of these entities’ performance. Therefore, since 1990, the management of Virginia Medicaid services for individuals with ID has been a joint effort of DMAS and DBHDS, combining the Medicaid expertise of DMAS with the ID services expertise of DBHDS. Through an interagency agreement, each department’s responsibilities regarding the ID and Day Support (DS) Waivers are enumerated. While some activities are the primary responsibility of one of the two agencies (examples below), the effective management of services for individuals with ID requires strong collaboration between both partners in areas such as the development and submission of waiver applications, regulatory packages, policy manuals and State Plan Amendments, and the development of budget proposals. The ongoing, collaborative relationship between DMAS and DBHDS will serve as a foundation for future efforts to improve waiver services for individuals with ASDs.

Table 1: The Administration Responsibilities for the Intellectual Disability and Day Support HCBS Waivers

TASKS	Lead Agency Responsibility	
	DBHDS	DMAS
1. Develop/Redesign waiver(s)	✓	
2. Develop provider manuals	✓	
3. Develop policy and regulations	✓	
4. Develop State Plan Amendments	✓	
5. Lead Advisory Groups of stakeholders	✓	
6. Develop provider communications/official	✓	

memorandums		
7. Respond to public/legislators about concerns about the waiver, slot distribution, and prior authorization procedures	✓	
8. Handle Appeals		✓
9. Manage waiting lists/distribute slots to CSBs	✓	
10. Perform Prior Authorization activities for the waivers	✓	
11. Provider training, technical assistance and consultation	✓	
12. Perform Quality Management Reviews		✓
13. Contract monitoring of Prior Authorization process		✓
14. Pay provider claims		✓
15. Complete federal reports, including the demonstration of cost effectiveness		✓
16. Develop provider rates	✓	✓
17. Budget monitoring/Accountability	✓	✓
18. Budget development/agency funding priorities	✓	

DMAS operates the IFDDS waiver, which is the primary waiver serving individuals with autism in Virginia today. The IFDDS, ID and DS waivers now support, together, approximately 8,800 individuals, while another 6,000 individuals remain on the waiting lists for these valuable services. All three of these waivers seek to address the needs of individuals with developmental disabilities, including those with ASDs.

Table 2: Description of Virginia’s Waiver Programs for Individuals with Developmental Disabilities (July 1, 2009 data)

Waiver	Population Served	Operating Agency	Currently Enrolled	Waiting List
IFDDS	Individuals above the age of 6 who have a developmental disability, but not MR/ID. Must meet the Level of Functioning Criteria.	DMAS	595	Over 1,000
MR/ID	Individuals under the age of 6 who are at developmental risk <i>and</i> Individuals with a MR/ID diagnosis. Must meet the Level of Functioning Criteria.	DBHDS	8152	5348
Day Support	Individuals with a MR/ID diagnosis. Must meet the Level of Functioning Criteria.	DBHDS	280	MR/ID Waiver Statewide Waiting list (see above)
EDCD	Individuals who meet nursing facility criteria. Must meet dependency criteria according to the Uniform Assessment Instrument.	DMAS	18029	No waitlist

Virginia Department of Education (VDOE). DBHDS, particularly the Office of Child and Family Services, and VDOE have worked closely for many years on areas common to the two agencies such as early screening and diagnosis and supports for transition aged-youth and families whose lives are affected by mental illness, intellectual disability, and substance abuse disorders. Recent collaborative efforts include development of the Early Intervention Autism Guidance Document, Awareness and Diagnosis Workgroup, co-membership within the Virginia Autism Council and jointly seeking grant opportunities to assist individuals with ASDs and their families. VDOE and DBHDS exchange information at least weekly in order to assist those within the developmental disability community.

Department of Rehabilitative Services (DRS). DBHDS and the CSBs have worked cooperatively with DRS for many years to promote the employment of individuals with ID, mental illness and substance use disorders through a variety of supported employment initiatives. Most recently, DBHDS and DRS are working together on the State Employment Leadership Network. DBHDS and DRS have also partnered for a number of years to provide OBRA-87 funding for needed specialized services for individuals with related conditions who reside in nursing facilities.

Virginia Department of Health (VDH). DBHDS has primarily worked with VDH through the Part C program, as both have the goal of systematically increasing the developmental screening, diagnosis and receipt of needed services among young children with developmental disabilities and related medical issues. DBHDS and VDH collaborated recently to submit a grant to the federal Department of Health and Human Services in the hopes of obtaining funding to improve services for children and youth with ASDs. While Virginia’s grant application was not

funded, the planning work that was accomplished has helped to provide the basis for some of the proposed joint efforts outlined in this document.

Public Safety Agencies. While DBHDS has worked for many years with public safety agencies and the courts regarding the forensic population, prevention activities for individuals with ASDs and other developmental disabilities, such as those described in Section 8, are a new venture for the Department.

The Community Services Boards as the Single Point of Entry

The JLARC study recommended DBHDS explore methods to improve case management of services for individuals with ASDs. It recommended examining establishing regional offices to provide case management, training family members to provide this service or expanding the role of existing case managers that serve similar populations in Virginia.

JLARC recommended DBHDS consider the following:

- Establishing a new network of regional offices to provide case management to individuals with ASDs or DDs. The office could provide case management services through all life stages and ensure there is no conflict of interest between those providing case management and those providing the services. However, a new network would require significant additional funding and new infrastructure.
- Training family members to provide case management services to individuals with ASDs. This option would ensure services were provided by someone known to the individuals and family. However, many families already provide this service informally to their loved ones and it is difficult to stay informed about services and resources.
- Establish CSBs as the case management provider for individuals with ASDs. This model would use an existing frame work – 40 local CSBs – to provide case management. CSBs currently provide case management to individuals with ID. Additional training and education would be required to ensure CSB case managers understand ASDs, treatment options and resources. However, this network is already in place and could mobilize quickly with additional funding.

DBHDS brought together a workgroup to examine these recommendations. The group determined the most effective mechanism to improve case management services for individuals and families was to leverage the professional case management expertise of those providing the service under the ID and IFDDS waivers.

Currently, individuals with ID receive case management through their local CSB (public case management), while individuals receiving IFDDS Waiver or on the IFDDS Waiver waiting list receive case management through their choice of private providers. In the model discussed by the workgroup, CSBs would not only be the single point of entry for those with ASDs seeking services, but also for the IFDDS Waiver and ID Waivers. Eventually, with appropriate funding, the CSBs would bear the responsibility for ensuring that all individuals with DDs, regardless of

ability to pay or Medicaid eligibility, receive needed case management services, either through a public or private provider. CSBs would thus act as the safety net for individuals with DD, as they currently do for individuals with ID, mental illness or substance use disorders. An integral part of this role is ensuring, with assistance from DBHDS, that there is a person-centered focus to service planning and delivery and that choice of type of case management provider is honored. Currently, entry into the IFDDS waiver is accomplished through one of the existing Child Development Clinics. There are only 12 such entities in the state performing screenings for IFDDS waiver services. Families must first locate the nearest site by visiting the DMAS web site and then seek an appointment at a Clinic, which may be a considerable distance from their home community. By contrast, there are forty Community Services Boards and each is well known in its local community for convenient access. Current case managers of the IFDDS waiver could contract with CSBs to continue to provide case management services following initial screenings.

As the single point of entry, services and assistance would be provided through the following steps:

- Once the CSB, as the single point of entry, is contacted, screening/assessment(s) is completed to determine the services the individual needs and for which he/she is eligible.
- Choices of services (including case management), for which the individual is eligible/needs, are presented.
- Families choose their providers. It would be expected that those providing case management are familiar with the locality in which the individual lives.
- Required annual eligibility re-evaluations for ID/IFDDS (and eventually a combined DD) Waiver services (i.e., Level of Functioning Surveys) will be completed by the individual's chosen case manager.

The group agreed that it is essential that choice of case management provider, like that of Waiver services providers, includes the following aspects:

- All case management entities are presented as equal choices.
- The individual/family is supported in choosing the type of case management entity that is right for them (e.g., small vs. large, public vs. private, appealing in philosophy).
- The individual/family is supported in their choice of a case manager.

The workgroup agreed that the State continue to provide oversight through the following agencies:

- DBHDS Offices of Licensing and Human Rights – all case management entities would be required to be licensed through DBHDS (and thus required to comply with Human Rights regulations as well).

- DMAS Quality Management Review and Utilization Review – offer quality assurance and financial oversight.

The work group also achieved consensus regarding CSBs as the appropriate venue for the provision of Information and Referral (I&R) Services to anyone with a developmental disability who asks for assistance in their community. CSBs' I&R duties will thus include:

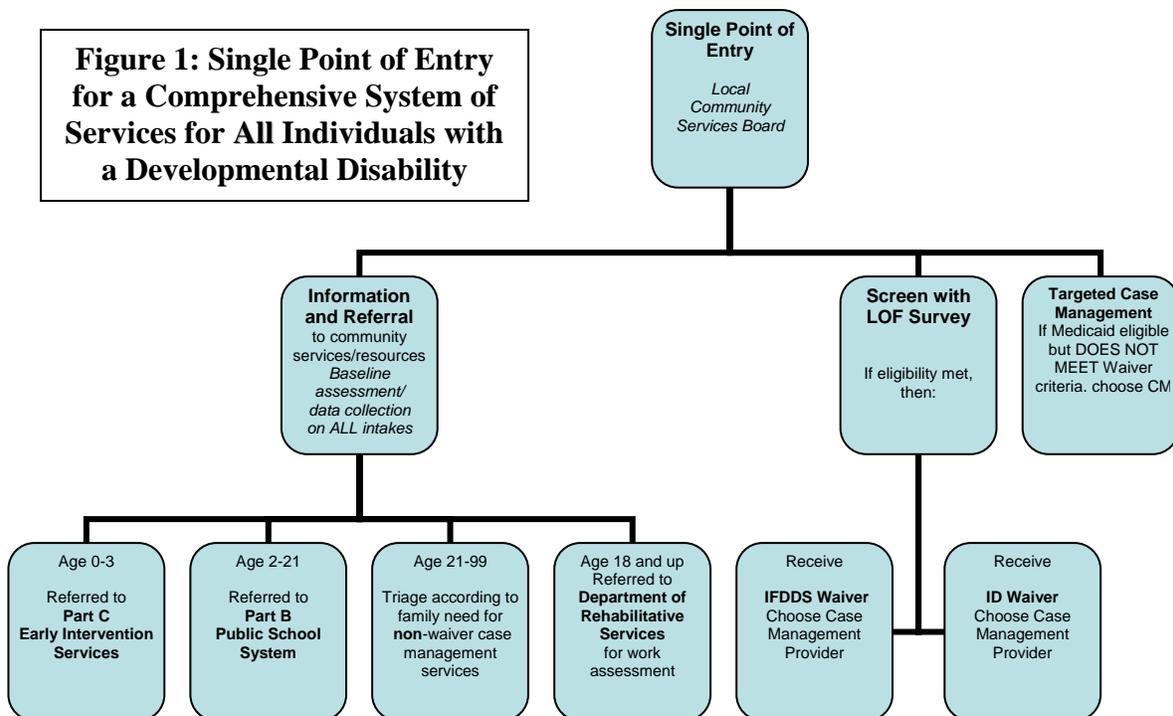
- Telephone consultations or face-to-face meetings with individuals seeking services
- The completion of needs assessments, with due consideration of Intellectual Disability, Mental Health, and Substance Abuse services eligibility
- Determination of individuals' eligibility for inclusion on ID or IFDDS Waiver waiting lists, the Elderly or Disabled with Consumer Direction (EDCD) Waiver, Early Intervention Services and other community services and/or state benefits
- Preparation and distribution of basic information, referral and resource packets to include fact sheets, relevant web sites, phone numbers to health lines, etc.

The VACSB has agreed that this I&R activity is a necessary function in order to build a state system for all individuals with DD. To facilitate this, DBHDS has added autism resource links to its website. In addition to linking to DBHDS' website for DD and ASD information, CSBs must post resources they offer to persons with DDs and ASDs on their agency websites.

This I&R function will also enable the CSBs to have the ability to collect data on the needs of constituents in order to assist with future planning and budgeting for state and local services. Information to be collected includes:

- For individuals with ASDs who are active in the CSB Service System - Annual reporting by CSBs, beginning FY2010, of persons with co-occurring ASDs receiving Mental Health, Substance Abuse and Intellectual Disability services .
- For individuals with ASDs who are not currently receiving services through their local CSB – Data collection, as individuals are made known to the CSB, to minimally include, the person's name, contact information, address, telephone and date of birth.

The cost of the additional I & R responsibilities for the CSBs can be mitigated through the transfer of the responsibilities currently given to the Child Development Clinics for screening for the IFDDS Waiver over to the CSBs. Along with the transfer of responsibility will also be the ability to bill for the services provided. Additional funding will be required in order to offer case management services and I&R services to all individuals with DD. The revised model, with CSBs as the single point of entry, is depicted in Figure 1 below.



The work group agreed that it is desirable for the future DD system in Virginia to encompass a birth to end of life continuum of supports. In this system, individuals will

- Be referred by their pediatrician or family doctor to early intervention services
- Be placed on a Waiver that is administered by their local CSB
- Receive services to ensure a productive, healthy life within their own community
- Have life-long support coordination (case management) within their local community via private or public providers.

Virginia’s future DD system will have as its goal a streamlined, cohesive structure in comparison to the current fragmented arrangement of resources.

While there is substantial support for the CSBs to be assigned the responsibility of the single point of entry into the DD system, there have also been concerns raised by various sectors in the developmental disability community. Most of these concerns are about the role of the CSBs as provider agencies along with being the local public entity responsible for intake and referral. The concerns stem from the premise that there would be less opportunity for choice of providers in a system where the initial contact into the system may also provide the services the individual is seeking. However, CSBs have been the single point of entry into the ID waiver system since its inception and must balance similar concerns. Despite the fact that many CSBs offer direct services, the private provider industry serving individuals with ID has grown substantially over the past two decades. There are currently more than 500 private providers of ID waiver services in

Virginia. Billing records provided by DMAS show that, for the past several years, only 23% of the ID Medicaid Waiver services are being billed by the CSBs, the remainder is done by private providers. If CSBs became the designated point of entry for Information and Referral and case management, they would be required to ensure individuals were guaranteed choice between all providers available, whether offered by the CSB or a private provider, just as they do now with the ID waiver services.

Establishing a Comprehensive Developmental Disabilities Waiver

Currently Virginia maintains two separate comprehensive waivers for individuals with developmental disabilities: the ID waiver and the IFDDS waiver. These waivers are accompanied by two separate waiting lists. As the individuals served by these waivers have similar and often co-occurring diagnoses, there is frequently confusion among individuals and their families as to which waiver is more appropriate, as well as which waiting list will lead to the receipt of needed services in the shortest amount of time. Children under the age of six years with any developmental disability or at developmental risk are only eligible for the ID Waiver. However, when they reach the age of six, if they have not received an ID diagnosis, they must switch to the IFDDS waiver, which may or may not have an available slot.

In recognition of these challenges, JLARC recommended DBHDS, in concert with stakeholders, examine combining these two waivers to improve services for the developmental disabilities population and reduce family confusion over waiting lists and services. A stakeholder workgroup was convened to discuss this option. The workgroup supported the idea of transitioning toward a single, comprehensive waiver for all individuals with developmental disabilities. The consensus of the workgroup was that this would help achieve parity in processes and services for all individuals with DD in the Commonwealth.

The services offered by the ID and IFDDS Waivers are identical, with two exceptions. The IFDDS Waiver contains one service not included in the ID Waiver: Family/Caregiver Training. The ID Waiver contains one service not included in the IFDDS Waiver: Congregate Residential Support. This service, in which individuals may receive residential supports in DBHDS-licensed sponsored residential homes, group homes or in supervised apartment settings at the same time as their roommates, is one which numerous IFDDS Waiver individuals and their family members have requested and from which they would benefit. Benefits would accrue from increased independence on the part of the individuals (being able to experience the natural milestone of moving out of one's parents' home), as well as increased peace of mind for parents/family members in knowing that their loved ones are living and receiving appropriate services in licensed, supervised settings, if that is the level of support that is required. Thus, combining these two waivers could provide individuals access to two services to which they were previously ineligible.

As a first step in a carefully planned and executed transition to a more streamlined and unified DD service system in Virginia, the stakeholder work group recommended that, prior to the merging of the ID and IFDDS waivers, DBHDS would assume responsibility for the day to day management of the current IFDDS Waiver, under DMAS' oversight, as is presently the case for the ID Waiver. This would allow time for the DBHDS staff, the CSBs and the providers of IFDDS services to become accustomed to working with each other on issues of mutual concern and interest as preparations are made for combining the waivers. It also assigns the responsibility for

managing the waiver to the agency now designated to lead developmental disabilities. Over an appropriate period of time, as recommended by the findings of DMAS and DBHDS and approved by the governor and General Assembly, the waivers could be carefully merged into one comprehensive DD waiver.

In recognition of the tremendous need for services, the 2009 Virginia General Assembly voted to eliminate the waiting list for the ID and the IFDDS Medicaid Waivers by FY 2018. At a minimum, they wanted to fund 400 hundred slots each year until the wait list was eliminated. Budget deficits since that time prevented that goal from being reached during the 2010 General Assembly session. While the pursuit of the elimination of the waiting lists must continue, Virginia needs to be looking for alternatives to its current Medicaid Waiver structure if this goal is to be realized. Placing the responsibility for all DD waiver services under the leadership of DBHDS, while working toward consolidation of waivers, will enable the Department to take the lead responsibility for this goal. DBHDS, working in concert with DMAS and its other partners to more quickly develop creative alternatives to the current system could help meet the goal of eliminating the wait lists by FY 2018.

To ensure that these two waivers are merged appropriately, a study would be conducted over a period of one year, with DMAS involvement. This study would need to examine how to resolve a number of challenges such as:

- The two waivers use different criteria for selection. The ID waiver wait list uses needs, urgent and non-urgent, to place individuals on the waiting list. The DD waiver uses a first come, first served methodology.
- Remedy differences in the payment system for the waivers' case management programs and ensure that all case managers receive appropriate training to understand autism and other developmental disabilities.
- Determine the increased costs associated with merging the waivers. While the services received under the two waivers are nearly identical (as mentioned above), individuals on the DD waiver do not have access to Congregate Residential Support as do those on the ID waiver. It will be important to determine any increased costs that may arise as the array of services available to the two groups becomes consolidated.
- Determine whether the Supports Intensity Scale, which is already being used to provide a standardized assessment of individuals with disabilities in Virginia, can be used to move to an Individual Resource Allocation methodology for the DD waiver. Individual Resource Allocation may permit Virginia to provide more flexible waiver options to individuals in need without significantly increasing costs.

Support for Providers of ASD Services through the DBHDS Office of Licensing

Pursuant to §37.2-404, this office licenses services providers offering treatment, training, support and habilitation to individuals who have mental illness, intellectual disability or substance abuse disorders; to individuals receiving services under the IFDDS Waiver; and to individuals receiving services in residential facilities for individuals with brain injuries. Licensing staff make

at least one unannounced inspection of service sites per year and investigate complaints about licensed providers.

The Office of Licensing has created criteria for providers to be recognized as having an ASD specialty. In order to be considered qualified to receive an “autism track” with the agency’s license, the Office of Licensing requires the applicant to have:

1. Documented organizational, supervisory and staff experience with supporting individuals with ASDs
2. Evidence of implementation of best practices in ASD supports with an expectation that some type of Applied Behavior Analysis be in use
3. Certification by staff and supervisors in ABA.

Currently, there is one provider in the state with this ASD specialty designation. Additional resources and staff should be made available to permit providers to receive ASD specialty designations. Workforce and provider readiness will be addressed in Section 3 of this document along with recommendations for expanding licensing resources in this area.

The Need for State General Funds for Family and Individual Supports

In the definition of developmental disability found in this section, there are three levels of support needed for individuals with ASDs and other developmental disabilities to ensure an adequately supported system. This plan discusses Medicaid and Early Intervention resources for individuals in Sections 4 and 5. There are also many individuals, both children and adults, who are need of supports and who do not fall into the categories that have already been described.

In the past, Virginia has provided state general fund dollars for family and individual support needs for individuals whose needs are fewer, but who nonetheless will not be able to fully integrate into the community without a basic level of support. As the system has evolved, more and more of the state general fund dollars have become used to draw down the federal Medicaid funds to serve the Medicaid eligible population, leaving those individuals who do not qualify for Medicaid without opportunity for supports. These funds should be made available through the CSB case management system to support individuals and their families as needed.

Family and Individual Support dollars should be made available to each CSB to fund, as needed, limited specialized supports to qualifying individuals and/or their families. Often, it is as simple as respite services funds or funding for job training needed by a young adult transitioning from school.

JLARC recommended that DBHDS work with partner state agencies, local government, non-profit, providers and advocacy entities to begin developing a coordinated, streamlined system of supports for individuals with ASDs and other developmental disabilities. As the designated coordinating agency, DBHDS convened several stakeholder groups to develop a common definition of developmental disabilities for Virginia, envision a single point of entry system

supported by local CSBs and determine steps to move toward one comprehensive developmental disabilities waiver for individuals with ID, ASD and other developmental disabilities. The recommendations in this section seek to outline the next steps required to fully achieve these goals and will be incorporated into the detailed, action plan in Section 9 of this document.

Section 1 Summary:

Recommendation #1: The General Assembly should adopt a single definition of developmental disabilities in Virginia. DBHDS recommends the definition outlined in this section.

Recommendation #2: Establish CSBs as the single point of entry for case management and information and referral in the Developmental Disability System, including serving individuals with ASDs.

Recommendation #3: In FY12, move the day to day administration of the IFDDS waiver from the Department of Medical Assistance Services (DMAS) to DBHDS, in order to realign and increase coordination of the Intellectual Disability (ID) and Individual and Family Developmental Disabilities Waiver Services (IFDDS) waiver programs for families.

Recommendation #4: Initiate a resolution in the 2011 Virginia General Assembly to require that the Department of Medical Assistance Services, as the single state agency designated in Virginia for the Medicaid Program, and DBHDS, the administrator of the ID Waiver, convene a work group of providers of current service and relevant stakeholders to conduct a study to determine the costs and parameters of combining the ID and IFDDS Waivers into one comprehensive waiver Developmental Disability Waiver. The study will include a comprehensive review of federal requirements related to combining the current CMS approved 1915 (c) waivers and consider the differences between the two waivers renewal dates. The study should also include the impact on and recommendations related to: 1) current waiting lists; 2) existing access and enrollment processes; 3) current case management systems; 4) services offered; 5) implementation of technology; and regulatory changes needed to support a combined waiver. The recommendations should be completed by November 30, 2011 for consideration by the 2012 Regular Session of the Virginia General Assembly.

Recommendation #5: Increase grants to localities to be used by the Community Services Boards as Family and Individual Support funds as needed for individuals who are not currently receiving or are ineligible for services under the ID or IFDDS waivers.

Section 2

Establishing a Centralized Source of Information Regarding ASDs

The JLARC study identified the lack of a consistent and reliable resource to find available information about autism as a major barrier for Virginia families seeking services. The JLARC report recommended the development of a centralized, comprehensive and reliable source of information to educate Virginians about:

- 1) Autism Spectrum Disorder
- 2) Research findings regarding treatment approaches and interventions
- 3) Publicly supported programs and services
- 4) Private providers specializing in ASDs
- 5) Support groups
- 6) Any other relevant information identified by stakeholders.

A workgroup was convened to address these recommendations. The group recommended there be a manned clearinghouse on ASDs operated directly by the state. While this recommendation has merit, it would be redundant for DBHDS to create such an entity that encompasses all of the recommended components. When reviewing resources currently active in Virginia, many information and referral sources already exist through non-profit, partially state-funded organizations and other private non-profit organizations such the Autism Society of America's chapter parent support groups and The Arc of Virginia. Since 2009, DBHDS has been partnering with other organizations to ensure the development and expansion of a statewide network that will provide accurate and timely dissemination of information concerning supports available to these individuals and their families.

Commonwealth Autism Service

Commonwealth Autism Services (CAS) currently maintains the largest statewide website on autism and provides information and referral services through a toll free number and website. CAS has received funding from the General Assembly for this purpose since its creation in 1995. CAS has recently redesigned their website at a cost of \$7,500 to increase visual appeal and contain the components recommended by the JLARC study. DBHDS will assist in marketing the CAS website as Virginia's primary, web-based source of information concerning ASDs.

CAS' website will have resource links to other parent support groups including all Autism Society of America chapters, which also have comprehensive resource listings for their local area. CAS will have other information concerning autism, such as public and private resources, funding source information, such as how to access Medicaid Waivers or Supplemental Security Insurance and National Standards on Evidence Based Best Practices for autism. CAS will also be responsible for continual review of their website to ensure the reliability of the information. DBHDS will collaborate with CAS to ensure information is timely and accurate. The CAS website addresses the JLARC recommendation of having a centralized, comprehensive and reliable source of information to educate Virginians about ASDs.

An additional resource facilitated by CAS has been the formation of Autism Action Groups (AAGs). AAGs consist of members of local communities who have a desire to actively and collaboratively work toward providing quality services and resources for individuals with ASDs within their own local geographical area. Representatives from each group meet monthly to network and share ideas and knowledge of resources in order to better serve those with autism within their own community.

In addition to these activities, CAS services include:

- Trans-disciplinary Diagnostic and Assessment Clinic©
- Public Safety Training
- Transition and Adult Services
- Partnership for Capacity Development in Public Schools©
- Training and Consultation
- Annual Conference
- Learning Institute

The Virginia Autism Resource Center

The Virginia Autism Resource Center (VARC) has been in operation since 1982 from a grant from the General Assembly and was the first autism organization in Virginia. For the first 26 years, VARC was operated exclusively by Grafton School. Since 2008, VARC has been a collaborative effort between Grafton School and Virginia Commonwealth University (VCU). Currently, VARC is the only statewide autism resource embedded within a university. Consequently, VARC has been able to leverage resources to engage in original research that establishes evidence-based practice. VARC's mission is to collaborate with individuals, families, professionals and agencies to build knowledge and skills so that those with ASDs can live, learn and work in the community. VARC attempts to accomplish this through:

- Raising public awareness about ASDs
- Empowering individuals with ASDs and their families
- Educating families, professionals and the general public on the many strengths possessed by people with ASDs and promoting respect
- Providing information, education and training to equip families and professionals with knowledge, skills and tools to effectively teach, support and guide individuals with ASDs.

VARC accomplishes this mission through providing an extensive free lending library, an updated and easy to use web site with online informational web cast and an extensive list of resources, and live training workshops. VARC is currently engaged in research to identify scientifically sound vocational programs for transition aged students and adults with ASDs. Additionally, through its collaboration with Grafton, Inc., VARC is completing action based research into the impact of data based decision making on IEP development and implementation.

Staff from VARC is active in many of the Commonwealth's committees addressing the needs of individuals with ASDs and supporting efforts to improve the capacity of the Commonwealth to serve individuals with ASDs across all ages at every level of impact. VARC's placement at VCU results in the availability of a post-baccalaureate certificate from the university

in Autism Spectrum Disorders. VARC staff is also integrally involved in the training of Positive Behavior Supports facilitators. Finally, through VARC's consultation, information, referral, lending library and program development, the agency provides direct services to nearly 3,000 citizens yearly across the Commonwealth.

In the coming years, VARC intends to further support the recommendations of the JLARC report by:

- Increasing the number of online, web services available to citizens
- Continuing to participate in state-wide committees addressing the needs of individuals with ASDs
- Providing training and resource referral
- Continuing to complete research to further guide practitioners in Virginia.

DBHDS as the Home for Autism

DBHDS will seek to continue coordinating these information resources through a variety of mechanisms including email, support groups, and CSB information and referral assistance. DBHDS has created an e-mail list of ASD support groups within Virginia and will ensure information concerning ASD at the state level is disseminated to these groups. DBHDS is working with these groups in order to gain further understanding of the needs of those with autism and ensure that their families' voices are heard at the state level.

DBHDS, working with all 40 CSBs, will assist with creating local community resource action groups where a CAS Autism Action Group does not currently operate. Each CSB is encouraged to develop a local group of stakeholders, or if one already exists, to become engaged with this group. DBHDS will assist any CSB in creating a DD Resource Support Group for their local area. Two CSB-initiated groups have been formed, one in Virginia Beach and another in Charlottesville. Additional groups are in the organizational phase at this time. See Appendix D for list of current Commonwealth Autism Service Autism Action Groups.

DBHDS staff has and will continue to collaborate with the state 2-1-1 Information and Referral System to ensure that accurate and timely information for autism services and supports are available through this 24 hour/day - seven days/week system. 2-1-1 VIRGINIA is a service of the Virginia Department of Social Services provided in partnership with the Council of Community Services, the Family Resource and Referral Center, CrisisLink, The Planning Council, the United Way of Central Virginia, and the United Way of Greater Richmond & Petersburg.

Section 3

Workforce Development

The JLARC study found that inadequately trained educational professionals and service providers can limit the effectiveness of therapies and treatment for children and adults with ASDs. These concerns are also well established for the broader developmental disabilities community. This section of the report discusses several current programs that are assisting professionals and providers in advancing their knowledge and expertise in provider services to individuals and families who are challenged with developmental disabilities.

Virginia Autism Council

The Virginia Autism Council (VAC) is an interagency council of ASD stakeholders that seeks to define needed skill competencies and to advance higher education, training and educational opportunities for personnel and caregivers supporting individuals with an ASD. To this end, VAC created “Skill Competencies for Professionals and Paraprofessionals in Virginia Supporting Individuals with Autism across the Lifespan.” This document has served as the foundational resource for professionals seeking to build knowledge and skills in the area of ASDs through multiple content areas. The VAC has revised and disseminated “Skill Competencies” in 2010, collaborated with agencies across the state to provide training on an array of ASD-related topics, as well as assisted DBHDS with meeting the recommendations of the 2009 JLARC report.

The revised and reorganized “Skill Competencies” underwent stakeholder review and include recent research from a variety of sources (National Professional Development Center on Autism, National Autism Centers National Standards Report, etc.), as well as terminology consistent with the use of Applied Behavior Analysis to provide a great behavioral focus.

Revised VAC “Skill Competencies:”

- General Autism Competencies
- Environmental Structure and Visual Supports Competencies
- Comprehensive Instructional Programming Competencies
- Communication Competencies
- Social Skill Competencies
- Behavioral Competencies
- Sensory Motor Development Competencies
- Independence and Aptitude Competencies

VAC has created a number of trainings on relevant topics related to ASDs. The trainings have been packaged and are designed to be used by both VAC members and other agency representatives as requested. The following trainings are available:

- Proactive strategies for early intervention service providers

- Proactive strategies for school age service providers
- Proactive strategies for adult service providers
- Asperger's Syndrome
- Strategies for parents who have children newly identified with ASDs
- Secondary transition for families

This year, as part of the current VAC work plan, specific goals and action steps were designed to target the recommendations of the JLARC report. The VAC will:

College/University Coursework

- Continue to review newly developed coursework / certificate programs to determine alignment with the *Skill Competencies*.
- Identify the impact the new competencies will have on course work. Create new criteria for coursework recognized by VAC and ensure this is in alignment with the *Skill Competencies*.
- Assist in the development of new coursework for professionals working with individuals with ASDs (online training for service providers).

Tuition Reimbursement

- Provide tuition reimbursement to public education participants completing recognized coursework in ASDs via VDOE funding.
- Work with DBHDS to create a system for tuition reimbursement for service providers should funding become available.

Website

- Maintain and update the VAC website, providing a clearinghouse for training endeavors taking place throughout the state, including access to the "Skill Competencies."
- Link to state ASD website, Commonwealth Autism Services, and additional resources.

Skill Competencies

- Present information regarding the newly revised *Skill Competencies* at conferences and workshops throughout the state.
- Distribute the revised *Skill Competencies* to professionals, paraprofessionals, and families.

Training

- Develop tools to evaluate trainings, determine outcomes and revise content and format as needed.
- Collaborate with three agencies to provide live training throughout the state (The Autism Society of America, DRS & VARC).
- Collaborate with early intervention providers to use the existing strategies training in the development of online training modules.
- Collaborate with adult service providers to use the existing strategies training in the development of online training modules.
- Revise, edit and script the "Newly Identified" Training. Create a training kit.

- Revise, edit and script the Asperger’s Training. Create a training kit.

The VAC will continue to review additional university programs that wish to obtain Autism Certificate Certification for class work that meets “Skill Competency” levels. DBHDS is seeking additional funding for tuition reimbursement for Early Intervention providers, Medicaid providers and family members who wish to take these classes and expand their ASD knowledge and skill sets. In order to provide tuition assistance for 200 persons at \$300 per class, a yearly budget of \$60,000 will be needed. The Tuition Reimbursement Program for individuals employed in a public or private school or enrolled in a teacher preparation program in the state of Virginia will continue to be supported by the Virginia Department of Education.

Tuition Reimbursement Funding for ASD Specific Coursework

The Virginia Department of Education provides funding for education professionals to access tuition reimbursement for VAC sponsored coursework through community colleges and universities throughout the commonwealth. In 2010 the Virginia Department of Education increased the funding for this initiative over 100% from its previous funding level.

Table 3: Eleven Community Colleges and Universities Carrying VAC Sponsored Coursework (October 2010)

Averett University	Old Dominion University
Longwood College	Radford University
Lynchburg College	Rappahannock Community College
James Madison University	Regent University
Mary Baldwin University	Mary Washington University
Virginia Commonwealth University	

DBHDS Training and Education of Providers

Since the inception of the ID Waiver services, DBHDS has employed five (5) regionally-based staff responsible for providing training and technical assistance to providers of case management and Waiver services, as well as to individuals with ID and their family members. Being regionally-based has made these “Community Resource Consultants” more accessible to providers in the five-designated “Health Planning Areas” of the state. In addition to responding to numerous telephone and electronic inquiries, they frequently go on-site to provide consultation regarding provider requirements, as well as best practices. Large-scale training events are coordinated and delivered by this group and on-line training modules have begun to be developed

on topics of relevance to case managers, service providers and family members. These highly trained and capable professionals could be leveraged further to train providers if a comprehensive Medicaid waiver for developmental disabilities is established.

DBHDS recognizes that additional training for private providers of supports to individuals with ASDs and other DDs is needed. This is particularly challenging considering the high rate of staff turnover in most provider agencies. Linkages to VAC or VARC sponsored training is one avenue. Another is the development of an on-line training module to be available through the DBHDS website.

In addition, DBHDS can improve the capacity and expertise of the provider workforce by partnering with local community colleges to offer a certificate in direct support services/management for persons with DDs. The Direct Support Professional Career Pathway (a partnership between DBHDS and the Virginia Community College system) is a recent effort to accomplish this goal. This initial project began in July 2010 through the Wytheville Community College.

Skilled direct support workers are essential to delivering high quality service to individuals with developmental disabilities and their families because they provide most of the hands-on support to these individuals. Direct support work is physically and emotionally demanding and the working conditions are often unfavorable when compared to alternative employment possibilities. Annual turnover and vacancy rates for direct support workers in DBHDS-operated facilities are among the highest for any role in State government.

To improve services, reduce high vacancy and turnover rates and create an improved learning environment for direct support workers, DBHDS community colleges, the College of Direct Support, and others have structured a three tier career pathway toward becoming a Direct Support Professional. It is hoped that this career pathway will support a more motivated, experienced and competent direct care staff pool and provide higher quality supports to individuals with developmental disabilities, including ASDs.

While this effort is in its early stages and currently involves only DBHDS facility direct support workers, an expansion of this model across the state to be made available to community service providers' staff would be highly beneficial.

Expanding Behavioral Supports

Classes leading to a Positive Behavioral Support Facilitator (PBSF) endorsement are offered through a cooperative agreement between DBHDS and the Partnership for People with Disabilities. These professionals offer consultation to families and services providers regarding positive ways to mitigate the challenging behaviors demonstrated by some individuals with DDs, including ASDs. The effort to increase the number of PBSFs statewide is funded through 2013, but financial support for this valuable effort beyond that date would be an asset to the state. In addition, an increase in the reimbursement rate for behavioral supports would assist in attracting more qualified professionals to this work in the Commonwealth. Virginia's \$70 per hour reimbursement rate is approximately \$10 under the national average for this service.

Regional Early Intervention Training and Technical Assistance in ASD

The Partnership for People with Disabilities at VCU (Virginia's University Center for Excellence in Developmental Disabilities Education, Research, and Service) currently administers two contracts with the DBHDS, Virginia's lead agency for the Part C early intervention system. Both of the contracts relate to Virginia's Comprehensive System of Personnel Development (CSPD) for the early intervention workforce.

The Integrated Training Collaborative (ITC) is the mechanism the Partnership established for overseeing Virginia's CSPD. The ITC brings together the experience and expertise of providers, family members, university faculty, Part C staff and other dedicated individuals to help implement training opportunities and enhance educational networking on behalf of infants and toddlers with developmental delays or disabilities and their families.

One priority of the ITC is the continued facilitation of regional Communities of Practice in Autism (CoPAs). The CoPAs were established in 2007 to serve as a means for regional problem-solving, for learning about evidence-based practices for serving children with ASDs and building local expertise in this area. There are nine CoPAs currently operating in Virginia, and each group has established priorities and developed an action plan for the year. The CoPAs have been, and will continue to be, an effective mechanism for informal support, networking and learning.

One need that has continued to emerge from the work of the CoPAs and through needs assessments of the early intervention workforce, however, is hands-on mentoring and coaching as a means of skill development and service delivery planning/implementation with individual infants and toddlers and their families. Practitioners have requested the expertise of trained professionals to assist with local direct service implementation at the child and family level.

The proposed project is designed to bring professionals with expertise in the area of ASDs to local early intervention providers. Based in the established Part C regions, the program specialists will be responsible for providing direct consultation to Part C teams, including family members, so that they can determine eligibility, develop effective Individualized Family Service Plan outcomes and plan interventions for infants and toddlers with ASDs. The goals for the program specialists during this one-year pilot project are to bring knowledge and expertise to local early intervention providers and to build the knowledge base of the early intervention provider community through mentoring and consultation.

At the conclusion of this special project, the provider community will have developed skills and expertise that can continue to be used with infants and toddlers served through the early intervention system. An evaluation plan will be developed and executed throughout the year to determine the change in provider knowledge as a result of the mentoring. The program specialists will use evidence-based and promising practices in their consultations, particularly those identified by the National Professional Development Center on ASD. The program specialists will also coordinate their work with the VDOE's Training and Technical Assistance Centers (T/TAC) statewide.

Many additional trainings and education opportunities are placed within the appropriate sections of this document in addition to those that are listed above.

Collaborating with Partner Agencies to Provide ASD Training Opportunities

DRS recently worked with the Virginia Autism Council (VAC), an interagency council of ASD stakeholders and experts, to develop and implement professional trainings for the DRS Woodrow Wilson Rehabilitation Center (WWRC) and Employment Services Organization (ESO) staff on strategies for supporting people that experience social, communication and sensory issues related to ASDs in an employment, community or training environment. In addition, DRS has sponsored training on a range of topics also focused on ASDs and employment, such as assistive technology for the workplace, effective school to work transition models, and vocational service models for persons with ASDs. Two new training opportunities that are currently in development include an online, self-paced training series that will cover vocational services and considerations for working with persons with ASDs and a DRS website with ASD specific tools, resources and vendors.

Another ASD and employment focused strategy that DRS is involved in a local Community of Practice model (CoP). In collaboration with George Washington University, DRS has provided training and technical support to establish the Northern Virginia Autism Employment Collaborative. The purpose of this CoP is to capitalize upon the knowledge and resources of a diverse group of stakeholder to develop a shared vision and enhance employment outcomes of individuals with ASDs in the Northern Virginia region.

To date, DRS has provided a range of training topics and formats to support DRS and ESO staff training regarding ASDs and is involved in several projects to expand access to training and resources on supporting persons with ASDs in employment. DRS will continue collaborating with partner agencies such as the VAC, VCU Rehabilitation Research and Training Center, Virginia Autism Resource Center, and The National Technical Assistance and Continuing Education Center at George Washington University to develop new training opportunities.

Section 3 Summary:

***Recommendation #6:* Develop an on-line training program and expand the DBHDS-community college certificate program for direct support professionals to promote a well qualified DD community-based workforce.**

***Recommendation #7:* Expand and develop Communities of Practice in Autism (CoPA) in order to develop skills and enhance service delivery planning/implementation through Part C Early Intervention.**

***Recommendation #8:* Increase by 50 the number of individuals trained and certified as Positive Behavior Supports Facilitators.**

***Recommendation #9:* Continued funding of the Virginia Autism Council through DBHDS for Council operations and tuition reimbursement for non-public education professionals and providers.**

Section 4

Improving Access to, Screening, Assessment, and Diagnosis of Children with ASDs

The JLARC study found that Virginia could significantly improve the lives of children with ASDs and their families and reduce costs to the Commonwealth with earlier diagnosis, screening, and treatment of children. Intensive early intervention has the greatest potential for improving outcomes and reducing future state expenditures. JLARC found two states had studied the costs avoided when Early Intensive Behavioral Intervention (EIBI) treatment was provided at an early age to children with ASDs. While intensive treatments such as EIBI are costly (ranging from \$23,000 to \$60,000 per year), costs of care are significantly reduced during school years and adulthood.¹ Using the methodology of these two studies, JLARC estimated that the Commonwealth could save approximately \$137,400 in special education costs per student if intensive EIBI was consistently provided to young children.²

A clear message from the ASD research literature is that “earlier is better.” The Centers for Disease Control (CDC) released new data in 2009 showing the average age at which children are diagnosed with an ASD is four and a half years. However, the average age of diagnosis in Virginia, according to a JLARC survey, was between 6 and 7 years.³

Early identification of the disorder and appropriate interventions lead to more successful outcomes for children. This message is echoed by the medical community. Both the American Academy of Neurology and the American Academy of Pediatrics (AAP) call for the routine screening for autism of all children, because children with autism who receive early identification and intensive intervention have the best prognosis. However, despite this understanding, many children are not screened at all.

Additionally, once a concern has been identified through developmental screening, there is often a lag in receiving a comprehensive diagnosis. As cited in the JLARC report, Virginians with ASDs must often wait for several months to receive a formal diagnosis and even longer for comprehensive assessments from interdisciplinary teams.⁴ A staff survey conducted by JLARC revealed that two-thirds of respondents waited for a diagnosis, a quarter waited one to two months, another quarter between three and six months and 18 percent waited longer than six months. Further, only eight percent of respondents indicated receiving a diagnosis from a multidisciplinary team, which is considered a best practice.⁵

JLARC identified several reasons that contribute to lack of screening and delayed diagnosis in Virginia:

¹ JLARC Study page 15

² JLARC Study page 15

³ JLARC Study page 54

⁴ JLARC Study page 58

⁵ JLARC Study page 58

- 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 diagnosis on the part of parents and physicians; and
- 4) Limited information about how to obtain services once ASDs have been identified and later diagnosed.

This section outlines efforts currently underway and those recommended to improve the depth and scope of early intervention activities in Virginia, particularly around awareness, screening and diagnosis. These efforts are achieved through valuable partnerships between Virginia's Early Intervention Program (Part C Program), VDOE's Part B Program, Virginia Department of Health (VDH) Child Development Centers and other offices and DMAS.

- *Virginia's Early Intervention Program (Part C).* The Infant & Toddler Connection of Virginia is Virginia's system of early intervention supports and services for infants and toddlers from birth through age two (and their families) who are not developing as expected or who have a medical condition that can delay normal development. The state Part C office is an organizational unit of the DBHDS. A wide variety of supports and services are available to eligible infants, toddlers and their families based on their individual needs. These supports and services include but are not limited to service coordination, developmental services, occupational therapy, speech-language pathology, physical therapy, assistive technology, audiology, nutrition, social work services, counseling, psychology services, vision services and transportation. Services are provided by through public and private agencies, by personnel who meet the qualifications of their specific discipline and who also are certified by DBHDS as Early Intervention Professionals, Early Intervention Specialists or Early Intervention Service Coordinators. Early intervention services are designed to meet the full range of developmental needs of each child and the needs of their families related to the child's development. Services are provided within the everyday routines and activities in which families participate and in places where the family would typically be, so that their daily life is supported and not disrupted by services. There are 40 Points of Entry, each serving specific cities and counties across Virginia.
- *Virginia's Part B Program.* Preschoolers (ages two - five) may be found eligible for Early Childhood Special Education services under one or more of 14 disability categories, which are defined in the federal and state regulations and include autism spectrum disorders. Local school divisions determine the criteria for being found eligible for services under the developmental delay category. Early Childhood Special Education services are provided by local school divisions.
- The goals, settings and support personnel needed to assist a child's growth are different for each individual. Staff from the local school system, with the child's family and other professionals as requested by the family, develops an individualized plan with goals and objectives to meet the child's developmental needs. The long term goal for preschool aged children is for them to be as ready as possible to enter kindergarten. The earlier services

are provided for children with disabilities, the better the long term prognosis. Children with special needs who have experienced support early in life do better in future settings. Research shows that participation in programs with typically developing peers is beneficial to all and enhances the language, social skills and participation in a typical curriculum. A smooth transition from early intervention to special education is also important.

- *DMAS' Early and Periodic Screening, Diagnosis, and Treatment Services (EPSDT) Program.* This is a Medicaid-funded State Plan service available to all Medicaid-eligible children under the age of 21. EPSDT is a comprehensive and preventive child health program which includes periodic screening, vision, dental and hearing services, with the goal being to keep children as healthy as possible. This is accomplished by assuring that their health and developmental concerns are diagnosed and treated as early as possible.
- In addition to health screenings and immunizations, other services such as personal care, assistive technology, private duty nursing and specialized behavioral rehabilitation and residential treatment services may be provided through EPSDT, when deemed medically necessary for the child. These types of services may be especially critical for children with developmental disabilities. In particular, one of the research-based treatments for ASDs, Applied Behavior Analysis (ABA), can be funded through EPSDT. See Section 5 for more information.

Information Regarding ASDs

The JLARC Report specifically recommended creating and adopting “Service Guidelines for Providing Early Intervention Services to Infants and Toddlers with ASDs.” The State Part C office that operates the Infant & Toddler Connection program will update and adopt these guidelines for serving infants and toddlers with ASDs in 2011, resulting in multiple benefits:

- The guidelines will provide greater direction to local Infant & Toddler Connection Program staff and providers for incorporating into their services the components of effective early intervention practices for young children with ASDs.
- The guidelines will be a useful tool for program staff and providers to educate families about ASD interventions and what they should expect from the Infant & Toddler Connection Program system.
- The guidelines will provide local Infant & Toddler Connection Program staff, service providers and families with consistent and current information as to the effectiveness of particular treatments.

The adoption of these updated guidelines will assist in ensuring more information is available to parents and providers regarding ASDs. In addition, the centralized resources that are currently under development or recommended in Section 2 of this report will assist in educating Virginia families about early signs of ASDs or other developmental delays and direct them to additional resources for information or screening. However, additional efforts should be extended to provide general education and awareness to Virginians about ASDs.

The Centers for Disease Control and Prevention have launched a “Learn the Signs” campaign as a national educational effort to increase public awareness concerning developmental milestones for both providers and the general public. Virginia should tap into these efforts to launch a statewide campaign in lieu of duplicating efforts of the federal Centers for Disease Control and Prevention.

In order to further improve awareness of ASDs and provide additional information about screening and its importance, JLARC recommended training of non-medical personnel as well. There are many non-medical organizations, such as day care providers, local Department of Social Services programs, preschool teachers and others that come into nearly daily contact with children and can be trained to identify signs of developmental delay in children. Once a potential delay is identified, these same non-medical providers could be trained on how to refer parents to screening resources and information.

- ***Recommendation #10: The State Infant & Toddler Connection (Part C) Program will finalize “Service Guidelines for Providing Early Intervention Services to Infants and Toddlers with ASDs,” by June 2011.***
- ***Recommendation #11: DBHDS will work with other state agencies to seek grant funding to establish a statewide public service campaign regarding early detection and screening for autism.***
- ***Recommendation #12: DBHDS will work with other state agencies to increase the capacity for screening for ASDs in a non-clinical setting, such as local Departments of Social Services, day care centers, Head Start/Early Head Start and other places that come into contact with young children.***

Screening

The purpose of screening is to identify children who *might* have a developmental delay or disorder, including an ASD. Identifying atypical or delayed development as early as possible is important so that children can access appropriate intervention. Screening tools are often developed for a specific problem or condition. The American Academy of Pediatrics recommends screening for autism at both the 18-month and 24-month well-child visits.

The screening process should involve three steps: 1) completion of a questionnaire by caregivers to assess social and communication development, 2) direct observation by the specialist and 3) review of clinical history. A variety of validated screening tools can be found at <http://www.firstsigns.org/screening/tools/rec.htm>. It is important that pediatricians be able to recognize the signs and symptoms of ASDs and have a strategy for assessing them systematically. Pediatricians also must be aware of local resources that can assist in making a definitive diagnosis of and in managing ASDs. The pediatrician must be familiar with developmental, educational, and community resources, as well as medical subspecialty clinics.

Current collaborations between VDH, DMAS, the Infant & Toddler Connection Program at DBHDS, and the Virginia Chapter of the American Academy of Pediatrics (VAAP) are working towards the education of physicians regarding the need for regularly scheduled

developmental screenings and how to bill for these services during office visits. Billing issues are a key concern to physicians because additional screenings mean longer office visits with their patients. It is the expectation of VDH, DBHDS, DMAS and VAAP that the systematic use of standardized tools for developmental screening of young children be spread statewide over the next several years.

VDH recently received a Virginia Systems Improvement (VSIP) grant of the Maternal Child Health Bureau State Implementation Grants for Systems of Services for Children Youth with Special Health Care Needs that is focused on developmental screening and promoting *medical homes* (see textbox). The VSIP grant also aims to increase capacity for developmental screening among home visitors, and to test the model of using *home visitors* (see second textbox) to better support medical homes.

The *medical home model* is a partnership between patients, primary care providers and families. The philosophy promotes care coordination related to the health status and developmental progress of the specific needs of a child and his/her family. The primary care physician in the medical home should be aware of the array of available subspecialty services, know when these services are needed, know how to gain access to and advocate for subspecialty care within health plans and know how to use subspecialists' recommendations and communicate the subspecialists' reports to the family. Medical homes for children with special health care needs incorporate the same elements of health supervision, community-based preventive care, developmental surveillance and anticipatory guidance used in the ongoing care of all children. Care should be accessible, comprehensive, continuous, compassionate, culturally effective and family centered. The medical home reinforces care coordination activities by the primary care practice team: the primary care physicians in collaboration with nurses, families, and support staff.

A *Home Visitor* is a professional who visits a family within their home, such as a representative of the Department of Social Services, Home Healthcare or Early

At this time, the VSIP grant activities represent VDH's capacity to promote medical home in practice by working with practices over time to develop the medical home model. This grant's learning collaborative will reach 15 primary care sites with a budget of \$220,000. In order to expand these activities to additional sites, additional funding will be required. These efforts will assist in promoting more screening among the medical community and ensure care coordination once a diagnosis is established.

Recommendation #13: Expand existing VDH medical homes initiative to assist physicians in creating medical homes for children with autism or other special needs.

Appropriate Referral and Diagnosis

If the recommendations at the conclusion of this section are implemented, parents and non-medical professionals may be aware of early signs of ASDs through enhanced public information and awareness. More screening may also be made available through additional collaboration

between state agencies and the pediatric community. However, without additional resources available for diagnosis, families may still encounter difficulties in getting needed assistance and services for their child.

The JLARC report noted that parents may experience delays between screening and diagnosis to confirm screening results. These delays, up to several months, while critical brain and physical development is underway, can be detrimental to children with developmental disabilities, particularly those with ASDs. JLARC also noted that it appears there are few professionals in Virginia qualified to make an ASD diagnosis and very few children are diagnosed via a multidisciplinary team, which is considered best practice.⁶

The ideal of a multidisciplinary diagnosis for children suspected of having an ASD involves recruiting, training, and retaining a team of professionals from different disciplines to provide diagnostic services to a designated region. This concept was also advanced in the JLARC study. The professionals involved in a regional diagnostic team should include a speech therapist, nurse, psychologist, social worker, occupational therapist, neurologist and educational consultant, among others. There are several efforts currently underway in Virginia to expand the availability of the multidisciplinary teams.

- *Commonwealth Autism Service.* Commonwealth Autism Service currently operates a clinic in Richmond and has helped develop model clinics in the Shenandoah Valley and is currently working with partners to replicate the model in the Lynchburg area, the Essex County region and in Abingdon. These clinics provide multidisciplinary diagnosis resources for families and professionals. It is CAS' intention to continue to develop clinics throughout the Commonwealth.
- *Virginia Leadership Education in Neurodevelopmental Disabilities (VA-LEND).* VA-LEND, which operates under the auspices of the Partnership for People with Disabilities at VCU, strives to assist in building capacity to screen and diagnose ASDs. VA-LEND is a federally funded, advanced level, interdisciplinary leadership education program. The purpose of the training grant is to prepare healthcare providers and special educators in the field of neurodevelopmental disabilities to assume leadership roles in the health care system and the community.

As part of their goals, VA-LEND will provide training in autism screening, diagnosis and treatment for two Autism Fellows (300+ hours of training) per year and at least 12 medium-term trainees (40-299 hours of training). In addition, one faculty member will become a certified Autism Diagnostic Observation Schedule (ADOS) trainer in order to increase the ADOS training capacity in the Commonwealth. VA-LEND also provides technical assistance and coaching to at least two interdisciplinary teams yearly in targeted areas, with a goal of increasing the number of these teams from seven to 12 by 2015.

VA-LEND has also implemented training for teams to provide multidisciplinary diagnostic evaluations in multiple locations throughout the Commonwealth. In FY 2010, training was

⁶ JLARC Study page 58.

provided for two community-based teams (school systems and clinic/school combinations). In FY 2011, training will be provided for three community-based teams.

- *Virginia Department of Education Part B Program.* One of the purposes of the Part B program is to increase regional capacity to provide identification and assessment services to individuals with autism. In order to address the immediate need for increasing the regional capacity of school divisions to accurately assess students with characteristics of autism the Virginia Department of Education sponsored four regional training sessions in the administration of the ADOS in 2010. These trainings were to address the need for educational professionals (autism specialists, lead teachers, educational diagnosticians, school psychologists, etc.) to be able to conduct assessments using the ADOS. The Virginia Department of Education has also equipped regional Training and Technical Assistance Centers (TTAC) throughout the state with the ADOS assessment kit to be used in local school divisions by professionals trained in its administration.
- ***Recommendation #14: The State Infant & Toddler Connection Program (Part C) will collaborate with the Virginia Chapter of the American Academy of Pediatrics to increase pediatrician knowledge base of how and where to refer families for interdisciplinary team diagnosis.***
- ***Recommendation #15: DBHDS, DMAS and VDH will work with the VAAP and Virginia Academy of Family Physicians (VAFP) Association to increase the periodic use of regular standardized developmental screening tools for all developmental delays, including autism.***

Section 4 Summary:

Information Regarding ASDs:

- ***Recommendation#10: The State Infant & Toddler Connection Program will finalize “Service Guidelines for Providing Early Intervention Services to Infants and Toddlers with ASDs,” by June 2011.***
- ***Recommendation #11: DBHDS will work with other state agencies to seek grant funding to establish a statewide public service campaign regarding early detection and screening for autism.***
- ***Recommendation #12: DBHDS will work with other state agencies to increase the capacity for screening for ASDs in a non-clinical setting, such as local Departments of Social Services, day care centers, Head Start/Early Head Start and other places that come into contact with young children.***

Screening:

- ***Recommendation #13:*** Expand existing VDH medical homes initiative to assist physicians in creating medical homes for children with autism or other special needs.

Appropriate Referral and Diagnosis:

- ***Recommendation #14:*** The State Infant & Toddler Connection Program will collaborate with the Virginia Chapter of the American Academy of Pediatrics to increase pediatrician knowledge base of how and where to refer families for full team diagnosis.
- ***Recommendation #15:*** DBHDS, DMAS and VDH will work with the VAAP and Virginia Academy of Family Physicians (VAFP) Association to increase the periodic use of regular standardized developmental screening tools for all developmental delays, including autism.

Section 5

Enhancing Early Intervention and Treatment for Children with ASDs

As noted previously, intensive early intervention services can improve outcomes for children with ASDs. The last section of this report noted the need to increase public awareness of ASDs, enhance the capability of pediatricians to screen for developmental delays including ASDs, improve the training for professionals to screen for ASDs and increase the availability of multidisciplinary teams to diagnose children with ASDs in a timely manner. This section of the report addresses how Virginia can improve its ability to provide intensive early intervention services and treatment for children once they have been diagnosed with an ASD.

The JLARC study found that both the Infant & Toddler Connection Program in Virginia (Part C) and the VDOE Part B program provide early intervention programs that can help children with ASDs. However, neither program consistently provides services that have been identified as best practices for treating children with ASDs. The JLARC study also found that additional coverage for services available through Medicaid and private insurance are inconsistently provided and may not cover all the services recommended for improving outcomes for children with ASDs.

This section outlines how services are currently provided for children with ASDs in Virginia and discusses gaps in the current network of services. The JLARC study recommended that the role of public and private sources should be explored to share the cost of better meeting the needs of Virginians with ASDs. A fully complementary system that provides adequate early intervention services to children with ASDs should offer services through:

- Early intervention programs such as Part B and Part C programs for children ages birth to five
- Financial needs-based Medicaid programs such as EPSDT
- Medicaid waiver programs for children who would otherwise require institutional level of care
- Private insurance coverage of services, where available.

The extent to which these four elements will provide complete access to all children with ASDs that require services depends largely on the resources available for the Individuals with Disabilities Education Act (IDEA) Parts B and C programs and the Medicaid program. Private insurance coverage can also have an impact on families who need services. All of these options and recommendations to provide a more complete system of coverage are discussed in this section.

Early Intervention Programs

Virginia has implemented state and local early intervention programs in accordance with IDEA. The Early Intervention Part C Program (the Infant and Toddler Connection Program) is administered by DBHDS Central Office and has 40 local programs that administer services across the Commonwealth. The program serves children from birth to age two. The Part B special education services program is overseen by Virginia Department of Education and administered by local school districts for children ages two to five years.

Current research suggests several elements of early intervention programs that are effective in improving outcomes for children with ASDs. The JLARC study summarized these key elements.⁷ They include:

- Family involvement;
- Individualized services;
- At least 20 to 25 hours per week of intervention for two to three years (intensity of intervention);
- Specialized curriculum;
- Structured environments that are predictable and follow a routine;
- Low child-to-staff ratios;
- Systematic instruction with research-based interventions;
- Qualified personnel; and
- Outcomes measurement for individual children.

The JLARC study found that while Virginia's Part B and C programs provided services with some of these characteristics to children, they did not provide all of them for children with ASDs. In general, services were individualized to each child. However, the intensity of interventions needed for children with ASDs was lacking. In addition, the Part C program, which for other developmental delays is focused on providing services in a child's home, did not provide the structured environment many children with ASDs might require. Perhaps, most troubling, at the local level, research-based interventions and best practices were not used consistently for either program.

The JLARC study recommended that Virginia examine whether changes to both the Part C and Part B programs could be made to provide more intensive and specialized services for young children with ASDs. The current programs are set up and operated to address the needs of children with a variety of developmental delays. However, these local program structures, may not provide adequate resources for children with ASDs. Both DBHDS, as the home of the Part C program and VDOE must examine the costs and value of establishing these intensive programs for children with ASDs. These needs should be studied and balanced with the needs of other children that may have different special needs and receive services through these programs.

DBHDS is required to keep data on children who are served by the Infant and Toddler Connection per Part C of IDEA. Part C served over 12,000 children in 2009. During 2009 only 27 children had officially received the medical diagnosis of ASD. Two hundred and twenty-two

⁷ JLARC Study page 75

(222) children were found eligible under the category of Atypical Development with behaviors that included “Impairment in social interaction and communication skills, along with restricted and repetitive behaviors.” These children are suspected of having an ASD but have not yet been through a diagnostic assessment. Even if all of the 222 children do have ASDs, these numbers are extremely low when considering CDC prevalence rates.

Table 4: Children with a Diagnosis of Autism or Suspected to Have ASDs

	New Autism Diagnosis	New Atypical Development with Autism Spectrum Disorder Characteristics	Total	Annualized Child Count	*December 1 Child Count
2007	42	236	278	11,095	6,023
2008	34	248	282	12,066	6,321
2009	27	222	249	12,017	6,288

*December 1 Child Count represents a point in time of children in the Part C system.

Recommendations in this report focus on bringing more resources to both the Part B and Part C programs to increase the availability of ASD-specific services for infants and toddlers. These recommendations complement other recommendations in Section 3 to continue to improve provider training and competencies to serve children with ASDs, including within the education system. In addition, there is a recommendation to improve outcomes measurement in the Part C program to ensure any additional resources are effective in serving children with ASDs.

- **Recommendation #16:** The State Part C Program should modify its data collection to track progress measures by disability, including ASDs. The State Part C Program should also collect specific disability information as part of its routine family surveys.
- **Recommendation #17:** The State Part C Program should provide a report to the General Assembly on the cost of establishing a specialized services program to serve young children with ASDs.
- **Recommendation #18:** The Department of Education should provide a report to the General Assembly on the costs of increasing the intensity, staffing and structure of preschool services for children with ASDs.

Medicaid Programs

The JLARC study found that while Virginia’s Medicaid programs have a significant role in providing services for children and adults with ASDs and other developmental disabilities, it is difficult for families to sort through the various programs and services to find one that meets their needs.

Virginia Medicaid has had a role in funding services specifically for individuals with developmental disabilities since the advent of Targeted Case Management and Day Health and Rehabilitation services in 1990. This was closely followed by the initiation of the Mental Retardation (now Intellectual Disability) Waiver in early 1991. While some individuals with

intellectual disability (ID) served by the State Plan Option and Waiver services also had other, co-occurring developmental disabilities (such as autism or cerebral palsy) in addition to ID, individuals with non-ID developmental disabilities received comparable Medicaid funded supports in 2000 through the IFDDS Waiver. Prior to 1990 and continuing through to the present day, some individuals with developmental disabilities have received Medicaid funding for needed community-based services through the Elderly and Disabled with Consumer Direction Waiver. It is clear that Medicaid has become a vital source of funding for supports for qualifying Virginians with developmental disabilities in the past 20 years.

The Role of EPSDT in Accessing ABA Services

As mentioned in Section 4, the Medicaid Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program is a comprehensive and preventive child health program available to all Medicaid-eligible children under the age of 21. While all Medicaid-eligible children can access periodic screening, vision, dental and hearing services in order to maintain optimum health, children with disabilities can receive services such as personal care, assistive technology, private duty nursing and specialized behavioral rehabilitation and residential treatment services according to their need through EPSDT.

Because EPSDT is a Medicaid State Plan service, children must meet Medicaid financial eligibility criteria. In general, children only meet these criteria if their *families* meet the Medicaid financial criteria. However, children approved for a Waiver program have financial eligibility determined on *their* income alone (i.e., family income is not considered). This means that a child, birth to six years of age, whose family income is more than 133% of the federal poverty level (\$29,327 for a family of four) or a child, six – 19 years of age, whose family income is more than 100% of the federal poverty level (\$22,050 for a family of four), would only qualify for EPSDT if he or she is also receiving waiver services. Therefore, many children who could benefit from EPSDT funded supports, including early intervention in the form of Applied Behavioral Analysis (ABA), cannot receive them because they are ineligible for them through Medicaid, nor are they covered by most private insurance policies.

Within the past year, DMAS has approved and defined a more specialized therapeutic intervention called Behavior Treatment within EPSDT. This service is available to all children receiving Medicaid and eligible for EPSDT who are deemed to have medical necessity and who are at risk of needing out-of-home placement due to the severity of their challenging behaviors. The current version of the EPSDT Behavioral Treatment program will allow only Intensive In-Home providers or those with an outpatient clinic license to provide services. From September 1, 2009 to August 31, 2010, 121 children have benefited from this intervention at a cost per child of \$7,151. This is not an autism specific or ABA specific service. Most children currently receiving this service are categorized as Emotionally Disturbed.

While board-certified Behavior Analysts (BCBAs) or board-certified Associate Behavior Analysts (BCaBAs), as well as Positive Behavioral Supports Facilitators (PBSFs) endorsed by the Partnership for People with Disabilities at VCU, may be reimbursed through EPSDT for services provided to individuals with ASDs (as well as other developmental disabilities) under a Licensed Intensive In-home (specifically Behavior Treatment) Services provider, few are able to meet the Intensive In-Home requirements. This License requires supervision by a Licensed Mental Health Provider (LMHP). The number of providers who are aware of this and in possession of the proper

DMAS provider agreement is limited. Currently there are only 25 providers statewide and very few of these providers provide a strict ABA therapeutic milieu.

Intensive In-home Licensed Services were designed as a Mental Health Service. The Licensing requirements for Intensive In-home Services do not align with the service requirements needed to provide ABA or Positive Behavioral Supports for those with autism. DBHDS created an Autism Specialty Endorsement for those who planned to work only with those with autism in an attempt to expand the provider base, and lowered the 100% LMHP supervision to 50% LMHP supervision, but even with the lowered requirement, providers were still unable to meet the Intensive In-Home requirements to become a licensed provider. The majority of ABA and PBS providers do not meet the LMHP requirements for Intensive In-Home and state that it is cost prohibitive to hire a LMHP, even part-time, just to meet licensing requirements in order to provide ABA and PBS services. Therefore, these providers need a new licensing category that more succinctly allows for the services that they currently provide and are needed specifically for those with ASDs.

Elderly and Disabled with Consumer Direction Waiver (EDCD)

Currently, over 1160 children under the age of 21 and 320 adults on the ID and IFDDS Waiver waiting lists are accessing services through the EDCD Waiver. These individuals must meet the EDCD Waiver's medical criteria (not all individuals with a developmental disability meet these criteria, so not all are eligible for EDCD Waiver) in addition to needing assistance with activities or daily living. The services offered through the EDCD waiver are prescribed by a physician and are related to medical needs identified by that physician. An added benefit for children receiving the EDCD waiver is that this also qualifies them for EPSDT services as well.

It is clear that some families can access ABA if they have limited resources to qualify for Medicaid. If these same families can navigate the current fractured system of waiver programs and supports, they may also access ABA and other services through the EDCD, IFDDS or ID waiver programs. The current burden to locate these services and resources is on families and may not be timely. According to the JLARC study, this is a significant impediment to families receiving services in a timely fashion for their children once a diagnosis has been made.

A Respite Waiver as an Option for Children and the Families

Respite services are typically needed by all families of children with disabilities. Respite provides much needed relief to families who are the sole provider of supports for their children. Families often cite respite as the one service that provides them with the ability to continue to provide the intensive support needed by their children. Upon diagnosis every child with a developmental disability should receive the Respite Waiver. As a Medicaid Waiver, this too would qualify children for EPSDT services if needed.

A Respite Waiver may serve as a vehicle to provide services to families who have no other access to Medicaid, waiver programs or needed services such as ABA through private insurance. It is recommended that a study be conducted to determine if a Respite Waiver that provides minimum services to families of children with developmental disabilities can be established so that all families can receive the benefits of a respite service as a first step in their ability to provide the care needed by their children. The added benefit of this would be that more intensive therapeutic interventions prescribed by a physician could then also be made available through

EPSDT. The study would have to weigh the costs of such a program with the benefits. In addition, it would have to weigh the value of such a waiver if Virginia chooses to move to one comprehensive DD waiver with individual resource allocation methodologies for funding. A comprehensive DD waiver may provide more value and services to these families over time.

- **Recommendation #19: DBHDS should seek emergency regulatory authority to include Intensive Individual Support Services as a new license provider category.**
- **Recommendation #20: DBHDS and DMAS should determine the level of need and associated cost of a Medicaid respite waiver to provide minimum services to children with developmental disabilities who meet waiver level of functioning criteria.**

Private Insurance

Early Intervention programs, such as Part C and Part B as well as Medicaid, clearly play a role in providing coverage to children who require intensive services for ASDs. However, the role of private insurance in providing coverage continues to be an issue of contention in Virginia. The JLARC study states that insurance coverage of ASD services is "consistent with the role of insurance," as indicated on page ii of the "Evaluation of Proposed Mandated Health Insurance Benefits, Evaluation of House Bill 83: Mandated Coverage of Autism Spectrum Disorders," September 2008. In other words, private insurance coverage has a role in assisting many families who need to access to treatment and services. In addition, the JLARC report noted that more than one solution, through a combination of public and private programs, is required to meet the service needs of all persons with ASD.

While treatment for medical conditions frequently associated with ASDs (such as digestive problems) are covered under health insurance, other treatments (such as Applied Behavioral Analysis based techniques, Speech and Occupational Therapy) are viewed by health insurers as educational or behavioral and therefore habilitative, versus medically necessary. However, medical experts indicate that even though there is often an attempt to classify ASD treatments as either educational or medical, many treatments can be considered both educational and medical. A child who receives a medical diagnosis of autism will not automatically receive the same educational diagnosis and therefore may not immediately be eligible for special education services through the public school system. Autism is a medical condition that is treatable but not curable. With treatment individuals with autism can improve.

The debate about private insurance coverage centers on whether Virginia should *mandate* coverage. A mandate would require all non-self insured health plans to provide some level of coverage of ASD-related conditions, such as OT, PT, or ABA. On January 13, 2010, two autism insurance reform bills were introduced; H.B. 303 by Delegate O'Bannon and S.B. 464 by Senator Howell. The bills would have required health insurance companies to provide coverage of the diagnosis and treatment of autism spectrum disorders for individuals age 6 and younger. Coverage for Applied Behavior Analysis (ABA) is subject to an annual maximum of \$35,000 and employers of 50 or fewer employees would be exempt. These two bills did not pass during the 2010 General Assembly Session. Another previous bill mandating coverage also failed to pass during the 2009 General Assembly session. Much of the discussion around these bills related to the costs and benefits to implementing mandated ASD coverage.

Twenty-three states now have autism insurance mandates that require the coverage of ABA services in addition to speech therapy, occupational therapy and other medical needs.

Table 5: States with Autism Insurance Mandates

Arizona	Iowa	Missouri	Pennsylvania
Colorado	Kansas	Montana	South Carolina
Connecticut	Kentucky	Nevada	Texas
Florida	Louisiana	New Hampshire	Vermont
Illinois	Maine	New Jersey	Wisconsin
Indiana	Massachusetts	New Mexico	

Minnesota, one of the first states (1997) to require comprehensive autism insurance benefits, reports that its premium impact has been \$0.83 per member per month. DBHDS put requests out to all states for input. Massachusetts, Colorado, Arizona, and Missouri report that they have recently passed insurance for autism, but it has not been in place long enough for them to be able to accurately report if insurance premiums have been affected.

There is concern that similar coverage mandates may increase health insurance premiums in Virginia. However, it may be possible to place within proposed legislation a drop out clause should premiums for an insurance organization rise by more than .01% within the first 3 years of such autism coverage. This may assist in alleviating the concern for out of control premium issues that has been expressed by the health care industry and small businesses.

As discussed earlier in this section, Medicaid provides greater coverage for developmental disabilities and delays, including Autism, than many private insurers. The federal government (through TRICARE, its healthcare plan for military personnel and their dependents) also includes some coverage of care and services for dependents with an ASD. TRICARE does provide limited coverage of ABA, for certain military dependents with ASDs. This coverage is available under a separate arm of TRICARE called the Extended Care Health Option (ECHO). ECHO services, including ABA, are limited to \$36,000 a year and are available to dependents of active duty service members only if delivered by a TRICARE-authorized provider. As of March 2008, TRICARE initiated its Enhanced Access to Autism Services Demonstration, which works to improve access to ABA services for children with ASDs. While the maximum allowable charges for services remains the same, the demonstration seeks to expand the availability of ABA services by expanding the definition of eligible ABA providers.

In addition to Medicaid coverage and TRICARE coverage that already exists in Virginia which cover evidence-based autism treatments, the General Assembly may consider revisiting the role of private insurance coverage for ABA and other services in upcoming legislative sessions. The JLARC study notes that Virginia could save \$137,000 in educational costs per student with autism over their educational tenure if *medically necessary treatments* were available to families through public or private programs. Early and adequate treatment could help reduce the need for ongoing supports over a child’s lifetime and reduce overall tax payer burden.

Should the legislature decide to consider an insurance mandate for autism, it is highly recommended that the covered services must be medically necessary and prescribed, provided or ordered by a health care professional licensed or certified in Virginia to prescribe, provide or order those services. Under this possible bill, "**medically necessary**" would mean: *the service is based upon evidence; is prescribed, provided or ordered by a health care professional licensed or certified under the laws of this state to prescribe, provide, or order autism-related services in accordance with accepted standards of practice; and will or is reasonably expected to do any of the following: (a) Prevent the onset of an illness, condition, injury or disability; (b) Reduce or ameliorate the physical, mental or developmental effects of an illness, condition, injury or disability; (c) Assist in achieving or maintaining maximum functional capacity for performing daily activities, taking into account both the functional capacity of the individual and the appropriate functional capacities of individuals of the same age.*

<p>Medically necessary - A service or treatment that is absolutely necessary in treating a patient and which could adversely affect the patient's condition if it were omitted.</p>
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Recommendation #21: In determining appropriate strategies for addressing the treatment needs of children with ASDs, Virginia should continue to strongly consider the role of private insurance in covering treatment in the continuing effort of public/private partnership in addressing the needs of those with autism.

Section 5 Summary:

Early Intervention Services:

- ***Recommendation#16: The State Part C Program should modify its data collection to track progress measures by disability, including ASDs. The State Part C Program should also collect specific disability information as part of its routine family surveys.***
- ***Recommendation #17: The State Part C Program should provide a report to the General Assembly on the cost of establishing a specialized services program to serve young children with ASDs.***
- ***Recommendation #18: The Department of Education should provide a report to the General Assembly on the costs of increasing the intensity, staffing, and structure of preschool services for children with ASDs.***

Medicaid Programs:

- ***Recommendation#19: DBHDS should seek emergency regulatory authority to include Intensive Individual Support Services as a new license provider category.***

- **Recommendation #20:** DBHDS and DMAS should determine the level of need and associated cost of a Medicaid respite waiver to provide minimum services to children with ASDs who meet waiver level of functioning criteria.

Private Insurance:

- **Recommendation #21:** In determining appropriate strategies for addressing the treatment needs of children with ASDs, Virginia should continue to strongly consider the role of private insurance in covering treatment in the continuing effort of public/private partnership in addressing the needs of those with autism.

Section 6

Improving the Education System for Children and Youth with ASDs

The JLARC study recommended that several steps be taken to improve the education system for children and youth with ASDs. Recommendations included development of operational guidelines on free and appropriate public education for students with disabilities, development of a model Individualized Education Plan (IEP) and establishment of transition guidelines for students with disabilities aging out of the education system. This section outlines the Virginia Department of Education's (VDOE) responses to these recommendations.

The VDOE has developed 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. These guidelines were developed through a collaborative and multi-stage research, development and review process. Guidelines from several other state departments of education were used as models, including Colorado, New Mexico, California and Ohio. Statutes, regulations, case law and policy provided a framework for expectations in educational goals and for the process of developing individualized educational programming for children with ASDs. Peer-reviewed educational, medical and psychological literature informed both the characteristics of students with Autism Spectrum Disorders and suggested instructional practices. To date, each draft of the guidelines has been reviewed by experts in the field of education for students with ASDs.

The guidelines are intended to provide practical guidance on ASD-specific instruction and professional development programs for school staff, parents, social workers, psychologists and physicians. Each of the four major guidance documents have been completed and are currently being edited and formatted within the VDOE in preparation to be released for the 2010-2011 school year. The documents address the following major topics.

ASD Guidance Document

The VDOE guidelines for autism spectrum disorders contain focus areas and resources directly related to the education and participation of individuals with autism in Virginia Public Schools. These guidelines are intended to serve as a resource primarily for educators, but may also be helpful to parents, medical professionals and other providers when they are making informed choices about the education of students with ASDs. The guidelines offer an overview of the current best practices for educating individuals with ASDs.

The Guidelines are not a standard of practice for the education of individuals with ASDs in Virginia. Rather, they are intended to serve as a resource for families, educators, service providers and others who seek to design educational programming for such students. The inherently individual nature of ASDs, the broad range and combination of abilities of individuals, and the legal mandates for individualized instruction necessitate thoughtful, informed consideration in educational programming design. Continuity across autistic disorders allows these guidelines to

address both the specific disability category of autism, as well as the more broadly defined group of Autism Spectrum Disorders. The contents of the guidelines represent the “recommended practices” available at the time of its creation. Below are the focus areas included in the document for additional detail.

- Foundational competencies
- Special education process
- Providing an effective education
- Considerations in educational programming
- Professional collaboration
- Family involvement
- Professional development
- Resources

Transition and ASD Guidance Document

The VDOE transition and autism guidance document contains the issues, challenges, and strategies that are specifically involved in helping young people with autism fully participate in society. The overall focus of the guide is on assessing the strengths and needs of young people with autism and designing the supports to expand opportunity and potential. Transition planning and composition is a critical area of need in supporting young adults with autism. The focus areas in this guide describe how to help persons with autism move from adolescence to adulthood and overcome the barriers that their disability presents. The unique needs of students with ASDs are taken into consideration in this document and guidance is offered for students with ASDs, their families and IEP teams to develop and implement quality transition plans and IEPs. The guide also discusses the specific issues to which transition teams should attend in supporting students with ASDs. Below are the focus areas included in this document.

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

Parents' Guide Document

The purpose of the VDOE parents' guide is to provide parents of students with ASDs information about the disorders across different ages and to discuss how ASDs may affect school-aged children and youth. Additionally, the guide presents parents with information about how to best partner with the school to ensure a quality education for their child and to implement interventions and carry over skills practiced at school into the home environment. The guide also provides parents with information that will assist them in understanding how to determine if a treatment approach is scientifically based and how to communicate with educational staff regarding other treatments they are implementing at home. The overall focus of the document is related to ensuring that parents have open communication with the school staff and are active partners in their child's education. Below are the focus areas included in this document.

- Description of autism and impact on learning
- The educational process (assessment, curriculum and Individual Education Plans)
- Life with autism in the home and the community
 - Use of positive behavior supports at home
 - Building social and communication skills
 - Communicating and collaborating with private providers and school personnel
- Resources
 - Parent Resource Centers
 - Teacher Training Assistance Centers (TTAC) Online
 - Special Education Advisory Committees and Lead Educational Advisory Committee
 - Due Process and Mediation
 - Parent Education Advocacy and Training Center

Model Program in ASD Guidance Document

The purpose of the VDOE Models of Best Practice document is to provide the tools required to uniformly meet the multifaceted needs of students with ASDs in the educational setting. The document outlines comprehensive information on the array of available research-based strategies and supports. Content will enable teachers and related services staff to identify and implement practices that have the desired effects on students' short-term functioning and long-term independence. Below are the focus areas included in this document.

- Model IEP document
- Curriculum framework
- Assessment framework and procedures
- Goal development
- Instructional strategies and considerations

- Addressing interfering behavior
- Educational strategies
- Focus areas for educational intervention
- Educational environment
- Organization and structure
- Collaboration with educational team
- Case studies
- Examples to demonstrate best practice

ASD RELATED PROFESSIONAL DEVELOPMENT

Center for Excellence in ASD

The Center includes a collaborative partnership between the Virginia Department of Education and Virginia Commonwealth University’s Rehabilitation and Research Training Center (RRTC) and School of Education. This center brings together noted experts and practitioners in the field of Autism Spectrum Disorders from a variety of professional perspectives. One of the center’s first major initiatives will be to assist the Department of Education in working with selected local school divisions across the commonwealth to improve their capacity to provide high quality programming for students with Autism Spectrum Disorders. This will be done through a support model that will provide a school division with qualified personnel that will coach administrators, teachers and paraprofessionals to improve their autism programs. All training and coaching is done on-site and strives to create long-term sustainable change.

In order to meet the needs for increased professional development in the area of autism throughout the state, VDOE is requesting \$750,000 to develop a six-university consortium to coordinate online professional development in the area of autism. This will also serve to prepare professionals with the coursework and supervision needed to achieve certification as a Board Certified Behavior Analyst (BCBA) or a Board Certified Assistant Behavior Analyst (BCaBA). This project will be a collaborative effort between a network of Virginia Institutes of Higher Education to improve the preparation of teachers, administrators, related service providers and paraprofessionals who work with students with ASDs. The Center for Excellence will strive to support this consortium by providing research based information, support in identifying quality instructors and collaboration with the Behavior Analysis Certification Board (BACB) for the participating colleges and universities in the development of associated coursework. Below are the key areas of focus for the initiative.

Eligibility

- Diagnostic teams
- Early intervention
- Adult service transition

Research

- Model development

- Technical assistance for long term sustainability
- Peer mentoring

Pre-Service and Professional Development

- ASD Consortium
- BCBA and BCaBA programs increased regionally
- On demand online professional development modules

Technical Assistance

- Product development
- Long term embedded technical assistance (behavioral focus)
- Regional and local technical assistance
- Self-determination

Family Involvement

Recommendation #22: Promote the professional development of educators in the area of ASD expertise by creating online coursework that will result in achieving certification as a Board Certified Behavior Analyst (BCBA) or a Board Certified Assistant Behavior Analyst (BCaBA).

SUPPORTING TRANSITION-AGED YOUNG ADULTS

Develop New Project SEARCH Programs

Project SEARCH is an employment program that is employer based and “where total immersion in the workplace facilitates the teaching and learning process through continuous feedback and application of new skills.”

(<http://www.cincinnatichildrens.org/svc/alpha/p/search/transition/default.htm>) Students may take part in three to four internships while in the program. Upon completion of the program a student is prepared to seek competitive employment with or without supports.

VDOE works with local businesses, state service agencies and public school systems in a partnership to create and sustain Project SEARCH locations. VDOE supported Project SEARCH sites are in Richmond City, Montgomery County, Norfolk City and Chesterfield County (partial support). Additional sites supported by the local school system or another source include Henrico County (VCU DRIP Grant), Williamsburg/James City, York County, Hampton/Newport News, Roanoke (4-6 school divisions). VDOE is also planning to support two additional sites in 2010. For additional details on Project SEARCH see Section 7.

Section 6 Summary:

Recommendation #22: Promote the professional development of educators in the area of ASD expertise by creating online coursework that will result in achieving certification as a Board Certified Behavior Analyst (BCBA) or a Board Certified Assistant Behavior Analyst (BCaBA).

Section 7

Services for Adults

Becoming independent as we grow into adulthood is often a process that is taken for granted. As the JLARC Report highlighted, persons with ASDs are not as likely to reach their potential for independence as other adults, even those with other disabilities. Most of the reasons for this are clear, “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.” The following section focuses on two critical elements in supporting adults with ASDs to become more independent, have a higher quality of life and, over the long term, require less services to maintain their independence; those are employment and housing.

EMPLOYMENT

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. 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 (in employment settings).

When a young, “neuro-typical” (i.e., a person without a disability) adult reaches the age of 16, he and his family may start seriously thinking about and planning for what he may do when he “grows up.” Ideally, when a young person with autism reaches the age of 16, the student and his family are also looking forward to exploring career interests, post-secondary educational options or trying different vocational interests. Unfortunately, as the JLARC report demonstrates, this is rarely the case for individuals with ASDs in Virginia.

There are inherent differences between the systems that support children in transition versus the systems that support adults due to the federal and state mandate of IDEA for a “free, appropriate, public education.” Services for adults with ASDs or DDs are based on eligibility criteria, not mandates. To further compound this situation, Virginia has historically and continually ranked among the bottom five states in the nation for spending on community-based supports for persons with DD, whereas we rank among the top ten in the country for per capita income. However, Virginia is not unique in struggling with this fundamental difference in structure between systems for youth and those for adults. Nationwide, stakeholders advocate for greater parity between educational services and adult supports.

The JLARC report has served as a catalyst for change in the way various agencies work together, share resources and face the challenges of supporting adults with ASDs. In the JLARC report, there were several key suggestions on how to improve the lives of adults living with ASDs and ways to increase their opportunities for greater independence. Three key areas were highlighted as being fundamental in achieving these goals: employment, housing and transition.

DRS Efforts on Behalf of Individuals with ASDs

When surveyed in 2008 as part of the JLARC investigation, “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 individuals with ASDs may be cost effective. Even before the issuance of the JLARC report, DRS had begun planning for this rising population.

The DRS has been quite active in building vocational services capacity for transition-aged students and adults with ASDs. DRS has partnered with agencies known for their excellence in vocational supports for persons with DDs and has allocated funding from its budget to pursue key initiatives to increase its capacity for working with this population. For example, DRS has:

- Hired additional staff experts
- Planned and offered trainings to vocational counselors/rehabilitation providers on ASDs
- Improved upon its services within Woodrow Wilson Rehabilitation Center (WWRC) by hiring new, highly trained staff
- Offered training to existing staff and increased “soft skills supports” (i.e., vocationally-related social skills, activities of daily living, etc.) for those with ASDs.

Participation in Evidenced-Based Research on ASD Service Models

The VCU ASD Career Links is a collaborative initiative between the Virginia Department of Rehabilitative Services and Virginia Commonwealth University to conduct evidence-based research on vocational rehabilitation (VR) services models for individuals with ASDs. The research covers four areas:

1. The impact of intensive, community-based work experiences on the employment outcomes of youth with ASDs
2. The postsecondary school participation and ultimate employment of college students with ASDs
3. The impact of personal digital assistants on the employment outcomes of individuals with ASDs
4. A longitudinal analysis of VR service delivery and employment outcomes among DRS clients with ASDs.

Over the 60-month period of this project, DRS and VCU will test, refine and implement new VR service models for individuals with ASDs. As a result of participation in this research project, DRS will establish best practices from research within the DRS system that are proven to improve the employment outcomes of individuals with ASDs.

ASD Service Enhancements to Woodrow Wilson Rehabilitation Center Life Skills Training Program

In 2009, WWRC expanded its Life Skills Training Program to serve an additional 114 individuals. This program expansion addressed the service needs of VR individuals with ASDs to enhance their social and other independent living skills, resulting in a 15% increase enrollment for this population. The WWRC Life Skills Training Program is a nine-week program that exposes students to basic life skills in an environment where they can “grow” their independence and social networking skills. Many participating students with ASDs report a significant improvement in social skills because of participation in the program. It is also critical to note that the rehabilitation rate (the percentage who complete their VR program and become successfully employed) of individuals who participated in Life Skills Training is around 70 %; almost 20% higher than those who did not participate in Life Skills Training at WWRC.

In addition, WWRC currently offers a staff facilitated ASD support group to help students deal with adjusting to campus life at WWRC. This support group has lead to greater opportunities for students to meet with peers to discuss and process challenges to support their success across center programs and activities.

Behavioral Supports Pilot Projects

DRS is piloting two projects in Henrico and Fairfax to evaluate the use of Applied Behavior Analysis (ABA) and Positive Behavior Support (PBS) as strategies for decreasing negative behaviors that interfere with employment outcomes for persons with ASDs. WWRC will participate in a three-year project to evaluate ABA as a therapeutic intervention to enhance employment outcomes for WWRC students. Information gathered from these pilot projects will support agency decisions regarding further implementation of agency behavioral support services programs.

Grants to Employment Services Organizations

DRS purchases employment and training services from over eighty Employment Services Organizations across Virginia. These organizations serve people with all types of disabilities. In 2009, DRS funded two grant programs designed specifically for people with a diagnosis of ASD. PRS, Inc. (formerly Psychiatric Rehabilitation Services) in Loudoun County was awarded a grant to establish a specialized community-based work adjustment training program designed specifically for youth with ASDs. This program is currently serving six youth. The goal of the program is competitive employment in jobs in the community. DRS also awarded a grant to Virginia Commonwealth University’s RRTC to support job placement and training for five Richmond area individuals with ASDs, with an emphasis on Asperger's Syndrome. This program has exceeded its expectations.

Project SEARCH

DRS has been involved in numerous internship and work programs over the last several years to provide work experiences for youth with disabilities. Project SEARCH, a national model being replicated in Virginia and mentioned in Section 7, has proven to be effective in providing work experience and assessment for youth with severe disabilities, including ASDs. As one of the four VCU ASD Career Links studies, DRS has worked collaboratively with VCU RRTC to develop and evaluate a SEARCH site that served exclusively students with ASDs. This grant project has proven to be very successful. In the 2010-2011 school years, DRS will support eight school systems as Project Search sites. Although not all students come with the ASD diagnosis, many do. DRS will integrate evidence-based practices identified through the VCU ASD Career links grant across all SEARCH sites that service students with ASDs. See block below for a detailed description of Project SEARCH.

Project SEARCH is a business-led transition program designed for students or adults with disabilities. The cornerstone of the one year program is immersion into a community based work experience at a host business site. During the internship period, individuals participate in three internships that each last 10 weeks. They meet in a classroom, within the business, in the morning and afternoon each day to learn other soft skills such as resume preparation, job interviewing and problem solving skills. Individualized job development and placement occurs based on the student's experiences, strengths and skills. In Virginia, several replications of Project SEARCH are occurring. In particular, the VCU Career Links program version of Project SEARCH, has successfully trained eight interns, six of whom are employed by the hospital where the project took place. For more info: www.vcu-autism.org

Increase in Numbers of DRS Applicants with ASDs

The Department of Rehabilitative Services is seeing a steady increase in applications for services by people with ASDs. In 2010, DRS served 1029 people with ASDs, up from 737 in 2008. In addition, in 2010, 88% of those served are transition age youth. These individuals often have higher support needs and thus require more extensive vocational rehabilitation services than other individuals with disabilities served by DRS. As stated throughout this document, DRS is building its capacity to serve this population by developing specialized services to meet the need. The federal Vocational Rehabilitation program requires matching dollars to access the program funds. State General Fund dollars appropriated to DRS are currently insufficient to respond to the influx of individuals with ASDs applying for vocational rehabilitation services. A General Fund appropriation of \$1,000,000 for case services to respond to this increased demand would help DRS build its capacity to best serve the population.

Preliminary findings of the VCU ASD Career Links research grant indicates specialty case loads are an effective practice for serving person with ASDs. DRS would be in a better position to create specialty caseloads if additional dollars and FTEs were allocated by the General Assembly to provide this support statewide. It is anticipated that additional FTE resources would be needed to support small caseload sizes and the provision of more intensive service models that would be engaged with local CSBs and local education authority staff to coordinate employment focused services. An appropriation of \$500,000 would allow the agency to establish five ASD specialty counselor positions in parts of the Commonwealth with high numbers of individuals with ASDs.

Current DRS data show individuals with ASDs require higher levels of employment supports to achieve successful employment. DRS administers the Long-Term Employment Support Services (LTESS) program to provide supported employment services to qualifying individuals beyond the 90 days allowed by the vocational rehabilitation program. DRS contracts with private Employment Services Organizations to provide these long-term support services. The program is funded exclusively with General Fund dollars and has the potential to ensure that individuals with ASDs who need ongoing support remain successfully employed. A study conducted by Dr. David Dean and his colleagues at the University of Richmond (2010) found that each dollar that was spent on follow-along services was matched by about \$3.40 in earnings. In FY 2008, people with ASDs represented three percent of all LTESS recipients. In FY 2009, that percentage increased to 5%. Because funding for the program is capped, and is not disability specific, not all individuals who require long-term supports are able to receive them. This program has received significant funding cuts over the last several years. As a result, many individuals with ASDs as well as other disabilities that require this service will not have access to needed funding. There are currently 1029 persons with ASDs enrolled in the vocational rehabilitation system. It is anticipated that a large percentage will likely require LTESS upon exiting the vocational rehabilitation system. These service supports are not currently available. \$600,000 would be required to address this need based on an anticipated yearly cost per person of \$3,000 for 200 people.

- **Recommendation #23:** Expand Department of Rehabilitative Services (DRS) case services to respond to the increasing demand for ASD services.
- **Recommendation #24:** Increase access to employment supports for up to 200 individuals through the long-term employment supports of the LTESS program.

Office of Developmental Services' Employment Related Efforts on Behalf of Adults with ASDs

In late fall 2009, the DBHDS Office of Developmental Services (ODS), began its response to the JLARC report by assembling a variety of stakeholders from across the state to form focus groups that examined the recommendations assigned to DBHDS. One of the fundamental differences between supports for those who are “above age 21” and those who are “below age 21” is the absence of federal and state mandates for those supports. In recognition of this, addressing issues pertaining to adulthood requires collaboration, the sharing of ideas and resources, but also the identification/creation of funding for any significant impact to occur.

ODS formed two workgroups to consider ideas and potential actions relative to JLARC study recommendations #17 (evaluating options for fostering greater independence among adults with ASDs) and #2 (state level accountability/coordination of services for Virginians with ASDs, enhancing access to information about community resources and improving the coordination of individual supports). The latter pertains to all ages but is extremely relevant to adulthood independence issues. The workgroup that addressed #17 developed a list of ideas/initiatives to pursue which included:

- Developing new or utilizing existing curricula for on-going training of direct support services staff on the characteristics and successful strategies for adults with ASDs
- Developing training plans and piloting various employment models for individuals with ASDs
- Investing in the improvement of Transition Councils regionally across the state to monitor and address the complex needs of transition-aged young adults with ASDs
- Developing a system of supports to provide adults with ASDs and other DDs with case management and services through public and private agencies in the Commonwealth.

The original workgroup that met to discuss recommendation #2, State Level Accountability and coordination of care, concluded with a core list of action steps that was vetted by The Advisory Consortium on Intellectual and Developmental Disabilities (TACIDD) at the group's April meeting. This work continued to be refined through a department head level committee, as well as a workgroup comprised of representatives from the CSBs, DD Waiver provider community, DMAS, advocates and other stakeholders. The final report of recommendations for an entire DD system change process is outlined in Section 1.

Simultaneous to the release of the JLARC report in June 2009, the ODS had already made significant investments in helping adults with DD (including ASDs) to become more independent. The Office brought aboard two new staff to assist DBHDS in becoming more inclusive of an overall DD population, building collaborations and relationships across historically disability groups, increasing and improving upon the capacity for serving children and adults with ASDs, as well as expanding housing and employment opportunities for persons with DD. Furthermore to improve outcomes for adulthood independence, ODS had also invested in the nationwide collaborative project "State Employment Leadership Network" (SELN). This project combines staff expertise from the Institute for Community Inclusion (University of Massachusetts, Boston) and the National Association of State Directors of Developmental Disability Services (NASDDDS) in an effort to help states to improve the integrated employment opportunities for the persons with DD that they serve. More specifically, the goal is to assist these individuals find community jobs earning minimum wage or more through the use of innovative models.

A large Virginia SELN advisory group has been formed, consisting of multi-agency/department, disability, and advocacy group stakeholders. This diverse group is in the process of proposing an "employment first" initiative for the Commonwealth, which emphasizes that everyone can work, regardless of disability. Upcoming activities may include:

- Recommendations for state policy changes
- Advocacy for regulatory and rate change to provide incentives for employment over day support services
- Public and business community awareness campaigns

- Trainings for self advocates on employment options, work incentives/benefits counseling and job skills
- Trainings on best practices in employment for persons with ASDs for providers of employment services across the state
- The formation of a “Promising Practices in Employment” team to develop, plan and implement a Project SEARCH for adults in the Northern Virginia area. Project SEARCH has proven to be an effective approach to employment for persons with ASDs. Although its history mainly involved transition-aged students, application of this model to adults with ASDs or other DDs has shown promise as well.

Continuation of the SELN is paramount to maintaining the momentum for assisting persons with DDs and ASDs to become employed in their communities.

In response to the JLARC report, which required DBHDS and DRS to identify and plan for effective employment programs specific to persons with ASDs, ODS and other DBHDS staff and stakeholders have researched and pursued information about promising and evidenced-based practices in employment supports for persons with ASDs or DDs. The results of this research were reported to stakeholders (via the “Collaborations” Conference, October 2010) as emerging and promising practices in employment supports for persons with ASDs.

Presently, the body of evidence-based research in vocational rehabilitation for persons with ASDs is very limited. In spite of that realization, we have identified two promising model projects within our state. One is the Fairfax Long Term Care Coordinating Council’s pilot program for employment supports for persons with ASDs. This is a collaborative project in conjunction with the Fairfax county regional DRS office and PRS, Inc. The emphasis is to help individuals with autism work on “soft skills” and to develop adaptive behaviors in preparation for a successful career opportunity. In addition, several licensed renditions of Project SEARCH have occurred across Virginia in the past 2 years.

As a result of HB 1099, ODS staff have consulted with staff from VCU’s RRTC to develop a plan for two related and innovative projects. The first is a series of replications of Project SEARCH for adults with ASDs or DDs. Project SEARCH (previously mentioned in Section 4) is a business-led transition program designed for students or adults with disabilities. Individualized job development and placement occurs based on the student’s experiences, strengths and skills.

The initial HB 1099 related “demonstration” project would take place in the Northern Virginia area. This region offers a dense population, many potential business opportunities with which to partner and a very strong network of providers and disability coalitions. An innovative approach, which is aligned with our state’s “employment first” stance is to partner with day support providers in the area of the designated business. Participants in those day support programs would be offered the opportunity to participate in career development and discovery processes in order to assess their interests and match skills for internships. The emphasis is on raising awareness within these traditionally segregated placements that the persons they serve can

and want to work. The second “phase” of this project would be to replicate this model up to three times across the state. Again, utilizing day support programs that are interested in acquiring new ways to support individuals with challenging behaviors and increasing employment skills and opportunities for the people they serve.

Recommendation #25: Increase employment skills and opportunities for adults with ASDs no longer in the school system, through a dual phase Project SEARCH model.

The second project in partnership with VCU/RRTC is to offer a set of regional trainings on autism work supports. The priority audience would be providers of waiver employment services (i.e., Employment Service Organizations), day support providers and individuals with ASDs and their family members. There would be a charge for these trainings, but the cost would be offset by resources from DBHDS. There is a great need for this type of training, as evidenced by feedback that providers and other stakeholders have provided to DBHDS staff. This particular approach was developed by VCU/RRTC staff and implemented in Texas within the Texas Vocational Rehabilitation System this past year. The target audience was rehabilitation services counselors, rehabilitation providers (i.e., employment providers), and others. The post-conference/training surveys indicate participants gained a great deal of useful knowledge and skills at a relatively low cost and time commitment.

Recommendation #26: Implement five (5) five-day, regional Autism Work Support trainings for a total of 750 participants, designed to increase the knowledge base of employment service providers, day support providers, individuals with ASDs and their family members about work supports for persons with ASDs.

Post-secondary Education Options

Asperger’s College Model© Commonwealth Autism Service has developed an Asperger’s College Model© program in partnership with United Methodist Family Services, Great Aspirations Scholarship Program and J. Sargeant Reynolds Community College designed to enhance the likelihood of college success and the acquisition of vocational skills for those with Asperger’s Syndrome. Planning is currently underway to replicate this model in other areas of the state.

Implementation of “Think College” initiative in Virginia. “Think College” is a project of the Institute of Community Inclusion at the University of Massachusetts Boston and TransCen, Inc. which as its aim the improvement and expansion of post-secondary learning opportunities for persons with Intellectual and/or Developmental Disabilities. Through a Think College mini grant from the Association of University Centers on Developmental Disabilities, Virginia Commonwealth University’s Partnership for People with Disabilities and Rehabilitation Research and Training Center convened the *Virginia Collaborative for College*. The Virginia Collaborative for College is a committed group of self-advocates, parents, state and local agencies and other organizations who came together for nine months in 2010 to craft a vision and action plan that will provide inclusive, individualized post-secondary educational experiences for young adults with ID/DD interested in attending post-secondary colleges, universities or technical schools.

Individuals with ID/DD and who are, or previously were, eligible for a free appropriate public education under the IDEA are the primary target population.

The Virginia Collaborative for College identified several key long term goals or outcomes necessary to ensure that the group's vision statement is fully realized:

1. There is collaboration among Virginia's secondary and postsecondary education systems, state agencies and community service providers to build a statewide infrastructure for inclusive, individual postsecondary education opportunities.
2. State policies and procedures are aligned to provide services and supports for individuals with ID/DD to access financial support and general access to postsecondary education opportunities.
3. Virginia General Assembly funding enables two and four year colleges and universities to build and expand postsecondary education opportunities for individuals with ID/DD.

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.

HOUSING

Affordable and accessible housing is a significant current and future issue for individuals with autism in Virginia. DBHDS staff regularly receive information and inquiries regarding housing crisis situations, indicating that the funding and service options are not currently adequate to meet the level of need. Aging parents of transition-aged, middle aged and even elderly children are not sure what will happen to their sons or daughters when they are no longer able to care for them in their homes.

During 2009-2010, a committee met in response to Item 315.Z of the 2008 *Appropriation Act* to study the housing needs of individuals with ID/DD and develop recommendations for better meeting the existing needs. The final report, "Report on Investment Models and Best Practices for the Development of Affordable and Accessible Community-Based Housing for Persons with Intellectual and Related Developmental Disabilities (Item 315 Z)," was submitted to the Governor and Chairs of the House Appropriations and Senate Finance Committees in November of 2009. It contained a thorough history of institutional housing and the significant loss of public funding individuals incurred upon moving into community housing.

This report concluded with a list of recommendations that DBHDS, in collaboration with the other involved agencies (VHDA, DHCD, VACSB, The Arc of Virginia and the Virginia

Network of Private Providers), determined to be critical in building financial and service capacity. The following highlights the steps that will be pursued in the coming biennium and beyond.

Suggested Action Steps from the 315 Z Housing Study

1. Develop a state policy and plan to expand critically needed community housing options.
2. Prioritize, target and align state agency investments of assistance.
3. Invest in the development of innovative housing and financing models that can effectively leverage affordable housing finance capital and private investor resources.
 - a. Build the capacity and willingness of the housing development community to provide desired community housing options
 - b. Establish program priorities for federal housing resources allocated to Virginia, including any National Housing Trust Fund resources, which are aligned with 14 state investment priorities for addressing the community housing needs of people with intellectual and related developmental disabilities
 - c. Direct the Virginia Housing Commission to study General Obligation bond use for housing in Virginia, including any Virginia-specific legal concerns.
4. Establish a community living supplement program for room and board to support the choice of community housing.
5. Convene a meeting of agency heads from DBHDS, VHDA and DHCD to consider the adoption of an updated Memorandum of Understanding.
6. Establish a permanent state source for education and training to provide a resource for CSBs and others to continually connect housing and the needs of people with intellectual and related developmental disabilities.
7. Direct the Disability Commission, through the state interagency Housing Expansion Task Force and in conjunction with the Housing Commission, to conduct an annual review of Virginia's implementation of these recommendations in subsequent years.

Response to the Housing Study and Promotion of Independence among Adults with ASDs

DBHDS has recently formed a Housing Implementation Team for developmental services, which will ensure alignment with the DBHDS Commissioner's Creating Opportunities Strategic Plan and the Governor's Housing Taskforce focal areas. The above recommendations will be reviewed and analyzed for timeline, priority and resource availability. The end result of this committee will be to execute those related goals. DBHDS, in addition to the other mentioned agencies or departments, may request funding supports from the General Assembly for the 2012 fiscal year and beyond to make an impact on reducing homelessness and increasing opportunities for affordable housing for persons with ASDs or DDs.

In addition, training of providers and families in effective residential supports (activities of daily living, positive behavioral approaches, social skills, etc.) is paramount for assisting adults

with ASDs in becoming independent in their home environments. As referenced in Section 3 of this report, Virginia has in existence or in planning numerous opportunities for supports training. The importance of a well trained staff or family cannot be undervalued.

Microboards

In order to assist families in accessing person-centered planning and community supports while they are waiting to access Waiver services, it is recommended that funding be established to assist in the creation of microboards for interested individuals. A microboard is a small group of committed family and friends who join with a person with a disability to create a nonprofit corporation for the purpose of developing the resources and support the individual needs to achieve his/her desired life outcomes and dreams. Since the microboard is a structured and legal entity, its purpose is to ensure that the person's circle of support will endure. Members of a microboard have a personal relationship with that person. They act as "bridge builders" to the community, and ensure that the person has opportunities to participate in his/her community in as many ways as possible.

Microboards ensure that the services the person receives are individualized to meet his/her needs and identify ways that the individual can contribute to his/her community. Thus, a microboard aids the individual in remaining active, engaged and a contributing member within his/her local community.

Although microboards are a form of "natural supports" (i.e., unpaid), training and assistance in the creation and maintenance of microboards will be necessary for family members and the individual with a disability. In order for this to be accomplished, it is recommended that funding be established for the creation of a MicroBoard Association for Virginia through the Request for Proposal (RFP) process by DBHDS.

Section 7 Summary:

- ***Recommendation #23:* Expand Department of Rehabilitative Services (DRS) case services to respond to the increasing demand for ASD services.**
- ***Recommendation #24:* Increase access to employment supports for up to 200 individuals through the long-term employment supports of the LTESS program.**
- ***Recommendation #25:* Increase employment skills and opportunities for adults with ASDs no longer in the school system, through a dual phase Project SEARCH model.**
- ***Recommendation #26:* Implement five (5) five-day, regional Autism Work Support trainings for a total of 750 participants, designed to increase the knowledge base of employment service providers, day support providers, individuals with ASDs and their family members about work supports for persons with ASDs.**
- ***Recommendation #27:* Create a MicroBoard Association for Virginia to assist adults with developmental disabilities to live independently using natural supports within their home communities.**

Section 8

Public Safety

Chapter 9 of the JLARC report, “Assessment of Services for Virginians with Autism Spectrum Disorders” provides an overview of current awareness of ASDs among Virginia public safety personnel. Chapter highlights include:

- Individuals with ASDs tend to encounter public safety personnel more frequently than the general population
- Individuals with ASDs 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
- Some of the characteristics and behaviors exhibited by individuals with ASDs can complicate the work of public safety personnel. These behaviors can easily be interpreted as aggression or resistance directed toward public safety personnel.
- Few public safety personnel in Virginia have received training to gain an understanding of ASDs, which could help them to more effectively work with people with ASDs.
- 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.
- Characteristics typical of ASDs (such as being non-verbal, unable to effectively communicate and naïveté regarding social situations) likely contribute to victimization.
- 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.
- Inappropriate encounters can create liability issues.
- While some public safety agencies have begun to provide their personnel with ASD awareness training, most agencies have not.
- There is no systematic ASD awareness training available to judicial personnel.
- Nearly three-quarters of criminal justice academies reported that they had never considered offering ASD training. Two-thirds of those academies indicated that the absence of a State requirement to offer such training influenced their decision not to offer training.

- Attempts to help a person with an ASD in an emergency situation may be misinterpreted or trigger an escalation in violent behavior.
- Several respondents to the JLARC staff survey of caregivers described problematic encounters with emergency medical personnel.

Most public safety agencies do not offer specific ASD awareness training to public safety personnel, but do offer a special needs training that includes autism in the Emergency Management Training Curriculum. The failure to learn the characteristics of ASDs may prevent public safety personnel from recognizing and reporting victimization, or cause them to misinterpret the behavior as defiance, non-compliance, as indicative of criminal intent when it is not. There is no comprehensive, systematic ASD awareness training available to public safety personnel at this time. Emergency Medical Service (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 not required to receive ASD specific training; however, the majority of firefighters are certified Emergency Medical Technicians (EMTs). EMTs and paramedics have had the opportunity to receive ASD awareness training at the State's EMS training conference.

The Supreme Court of Virginia and Commonwealth's Attorney's 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.

Training for individuals with ASDs and their caregivers on how to work in cooperation with public safety personnel would be beneficial to the ASD community. The current lack of awareness and recognition of ASDs on the part of public safety personnel complicates their work when they encounter an individual with an autism spectrum disorder.

The Public Safety Workgroup (PSW), which formed as a partnership between Commonwealth Autism Service and Project Lifesaver International, confirmed the results of the JLARC study. In late 2009, the workgroup was asked by DBHDS to respond to recommendations 18, 19, and 20 of the JLARC recommendations.

The PSW has set for itself the following goals in order to remediate the current limitations in ASD training and awareness activities available to Virginia public safety representatives:

- 1) At least one general instructor in each training academy will be certified to teach ASD awareness training.
- 2) 100% of new training academy cadets will receive ASD awareness training.
- 3) Multiple comprehensive training modules, using a variety of training techniques and tools, will be developed and provided in a variety of settings.

- 4) ASD awareness will be increased by offering training opportunities in several locations across Virginia.
- 5) The integrity and consistency of the training will be protected by the maintenance of a core cadre of instructors.

In order to achieve the above goals, Commonwealth Autism Service dedicated a full time staff person to assist with the newly created Public Safety Workgroup. This staff person’s role is to communicate and collaborate with public safety agency representatives, as well as to identify and/or develop training tools that can be used to provide ASD awareness training for all public safety personnel.

The Public Safety Workgroup will:

- Continue to meet monthly via online meetings, conference calls, or in person until all activities identified in the action plan have been completed.
- Define and develop a Basic Training program.
- Define and develop in-service training modules.
- Offer a minimum of five training opportunities a year to public safety personnel, in various regions across Virginia
- Develop a training budget.
- Seek funding to provide training. Funding sources could include the Virginia General Assembly, public and private foundations or corporate and private donors. PSW agencies will develop letters of support to use for solicitation of funding.

Public Safety Workgroup Action Plan

Due Date	Activity	Responsibility	Notes
November 2011	Establish training standards to include awareness lesson plans	Department of Criminal Justice Services	
	Develop and publish a model policy for enforcement personnel regarding ASD awareness	Department of Criminal Justice Services	Policy will be distributed to all public safety agencies and interested parties.
	Establish a link to autism information resources on agency website	Virginia Fire	
	Update and modify current ASD	VDH/OEMS/VFP	

	training materials		
	Identify a core cadre of certified general instructors to be “ASD Awareness Trainers”	PSW	
	Have 100% of new officers trained with basic training program	PSW	
	Design and develop basic ASD training	PSW	Basic understanding of autism
	Design and develop in-service training modules	PSW	
	Offer 5 training opportunities targeted to law enforcement personnel	PSW Trainers	In 5 different regions
November 2012	Add Fire and EMS as a target audience	PSW	
November 2013	Add courts, attorneys and judicial personnel as a target audience	PSW	
November 2014	Add parents and caregivers as a target audience	PSW	
November 2015	Add private security as a target audience	PSW	
	Have training materials accessible online	PSW	
Ongoing	Continue to chair Public Safety Workgroup	Commonwealth Autism Service	
	PSW agencies will provide letters of support of training and ASD funding	PSW	
	Maintain roster of trained general instructors	PSW	
	Develop and maintain an archive of PSW activities	Commonwealth Autism Service	Shared with all agencies
	Maintain training evaluation summaries	Commonwealth Autism Service	Shared with all agencies
	Collect current training materials	Commonwealth Autism Service	Reviewed by all PSW agencies
	Consistently update training materials with recent statistics/research interventions and strategies	PSW	
	Seek and apply for ASD awareness funding	PSW	

Workgroup Activities to Date

To date, the Public Safety Workgroup has met 9 times, and collaborated numerous times via telephone calls and email. The group has identified training needs, ways to meet the training needs of public safety personnel, reviewed training materials from a variety of sources, and researched best practices.

Workgroup expenses to date include personnel costs to participate in meetings, including salaries and travel expenses, training materials, and personnel costs to research training other states have implemented. Workgroup members have contributed over 1,716 hours for meetings and research. Additional workgroup contributions include travel expenses to meetings, training materials and meeting locations.

The Public Safety Workgroup has concluded that:

- Public safety personnel are seeking ASD training and ASD training is critical to protecting the health and safety of the community.
- All participating agencies will use the same curriculum in order to maintain consistency in all agencies.
- Funding will be critical in order to successfully complete the action plan. Budget requirements will include compensation for instructors (including instructor fee, mileage and other travel expenses), audio/visual equipment (LCD projector, laptop and accessories for sound) and training materials (manual, instructor's guide, ASD awareness cards, videos, CDs, etc.). Further, the workgroup realizes that additional staff will be needed to coordinate workgroup activities.

Training for Public Safety Personnel

Implementation of training will involve travel to five regions in Virginia in order to train other public safety personnel to become instructors, utilizing a "Train-the-Trainer" model, increasing the number of instructors available in each region. Agencies receiving training will pay for training via budgets; however, a pool of funds should be made available for agencies that are unable to pay for the training. The Public Safety Workgroup respectfully requests that funds be appropriated to support development and implementation of the training curriculum developed by this workgroup.

Commonwealth Autism Service serving in both a leadership and secretarial capacity will manage the funding and provide the project coordinator and administrative support staff. The Office of the Secretary of Public Safety is kept updated via communication with the Department of Criminal Justice Services.

Budget for Workgroup Activities

The Public Safety Workgroup has identified the following recommendations and associated budgetary needs in order to develop the training curriculum and begin implementation of action items identified for year one of the action plan:

Recommendation #28: ASD Training developed by the Public Safety Workgroup should be recognized as the minimum training standard in the Commonwealth of Virginia for all public safety personnel.

Recommendation #29: All public safety personnel (including judges, magistrates, attorneys, law enforcement, fire/EMS, etc.) should receive basic autism awareness training (developed by the PSW) to understand characteristics of autism.

Recommendation #30: The General Assembly should require all public safety personnel to receive ongoing in-service training for a more in-depth understanding and awareness of autism spectrum disorders, including current strategies and interventions to use during an encounter with an individual with autism.

Recommendation #31: The General Assembly should provide a pool of funds for public service agencies to access when they are unable to pay for ASD awareness training.

Section 9

Detailed Action Plan

This report was developed in response to the 21 recommendations made by JLARC in June 2009 to improve the manner in which Virginia serves individuals with ASDs. This report outlines the findings from the JLARC report, describes current efforts underway to address the findings and proposes additional recommendations to further advance Virginia from a fragmented system serving some individuals in need to a comprehensive system that provides coordinated and evidence-based services to children and adults with ASDs as soon as feasible.

This Section summarizes the recommendations from this report and provides a detailed action plan for moving from the fragmented system to a comprehensive system. Many of the recommendations in this report require additional state and local funding. Given the Commonwealth's and the nation's fiscal realities, it may be difficult to fund these services in the short-term or expand them over time. The action plan at the conclusion of this Section recognizes these fiscal realities and attempts to prioritize based on these realities. The recommendations in this report can be grouped into four major categories for planning purposes.

Establishing a More Coordinated System of Care with Statewide Accountability

Throughout its work with other agencies and stakeholder groups, DBHDS found that the current system, while moving in the right direction, is fragmented, uncoordinated, and lacks focus or clear goals. The JLARC report supports these findings as well. The recommendations in this category support moving to a more integrated system where policies and services can be better coordinated and families can have easier access to support and services.

- *Recommendation #1:* The General Assembly should adopt a single definition of developmental disabilities in Virginia.
- *Recommendation #2:* Establish CSBs as the single point of entry for case management and information and referral in the Developmental Disability System, including serving individuals with ASDs.
- *Recommendation #3:* In FY12, move the day to day administration of the IFDDS waiver from the Department of Medical Assistance Services (DMAS) to DBHDS, in order to realign and increase coordination of the Intellectual Disability (ID) and Individual and Family Developmental Disabilities Waiver Services (IFDDS) waiver programs for families.
- *Recommendation #4:* Initiate a resolution in the 2011 Virginia General Assembly to require that the Department of Medical Assistance Services, as the single state agency designated in Virginia for the Medicaid Program, and DBHDS, the administrator of the ID Waiver, convene a work group of providers of current service and relevant stakeholders to conduct a study to determine the costs and parameters of combining the ID and IFDDS Waivers into one comprehensive waiver Developmental Disability Waiver. The study will include a comprehensive review of federal requirements related to combining the current

CMS approved 1915 (c) waivers and consider the differences between the two waivers renewal dates. The study should also include the impact on and recommendations related to: 1) current waiting lists; 2) existing access and enrollment processes; 3) current case management systems; 4) services offered; 5) implementation of technology; and regulatory changes needed to support a combined waiver. The recommendations should be completed by November 30, 2011 for consideration by the 2012 Regular Session of the Virginia General Assembly.

Expand the Array of Services to Address Unmet Needs

DBHDS also found, in working with stakeholders and state agencies, that there are many limitations on the services available from birth to adulthood for individuals and families affected by ASDs. A much broader array of services that focus more clearly on early screening and diagnosis, intensive and structured early interventions for children, and evidence-based services, offered through public and private mechanisms, for children and adults is required to ensure individuals receive the supports they need for a full life in our communities.

These needs often require additional state and local funding. Given the Commonwealth's and the nation's fiscal realities, it may be difficult to fund these services in the short-term or expand them over time. The action plan below recognizes these fiscal realities and attempts to prioritize based on these realities.

- *Recommendation #5:* Increase grants to localities to be used by the Community Services Boards as Family and Individual Support funds as needed for individuals who are not currently receiving or are ineligible for services under the ID or IFDDS waivers.
- *Recommendation #13:* Expand the existing VDH medical homes initiative to assist physicians in creating medical homes for children with autism or other special needs.
- *Recommendation #17:* The State Part C Program should provide a report to the General Assembly on the cost of establishing a specialized services program to serve young children with ASDs.
- *Recommendation #18:* The Department of Education should provide a report to the General Assembly on the costs of increasing the intensity, staffing and structure of preschool services for children with ASDs.
- *Recommendation #20:* DBHDS and DMAS should determine the level of need and associated cost of a Medicaid respite waiver to provide minimum services to children with developmental disabilities who meet waiver level of functioning criteria.
- *Recommendation #21:* In determining appropriate strategies for addressing the treatment needs of children with ASDs, Virginia should continue to strongly consider the role of private insurance in covering treatment in the continuing effort of public/private partnership in addressing the needs of those with autism.

- Recommendation #23: Expand DRS case services to respond to the increasing demand for ASD services.
- Recommendation #24: Increase access to employment supports for up to 200 individuals with autism through the long-term employment supports of the LTESS program.
- Recommendation #25: Increase employment skills and opportunities for adults with ASD no longer in the school system, through a dual phase Project SEARCH model.

Continue to Advance Provider and Educator Development and Training

In partnership with state and local agencies, as well as the many stakeholder entities that have served families affected by ASDs in Virginia, there has been a long-recognized need for additional provider and workforce training and development. The JLARC report also emphasized the need for additional training for physicians, educators, care providers and others. The recommendations in this report focus on building upon the many efforts already underway in this area. While some of these items have a cost associated with them, the value received for the limited investment in funding can be quite high.

- Recommendation #6: Develop an on-line training program and expand the DBHDS-community college certificate program for direct support professionals to promote a well qualified DD community-based workforce.
- Recommendation #7: Expand and develop Communities of Practice in Autism (CoPA) in order to develop skills and enhance service delivery planning/implementation through Part C Early Intervention.
- Recommendation #8: Increase by 50 the number of individuals trained and certified as Positive Behavior Supports Facilitators.
- Recommendation #9: Continued funding of the Virginia Autism Council through DBHDS for Council operations and tuition reimbursement for non-public education professionals and providers.
- Recommendation #10: The State Infant & Toddler Connection Program will finalize “Service Guidelines for Providing Early Intervention Services to Infants and Toddlers with ASDs,” by June 2011.
- Recommendation #14: The State Infant & Toddler Connection Program will collaborate with the Virginia Chapter of the American Academy of Pediatrics to increase pediatrician knowledge base of how and where to refer families for interdisciplinary team diagnosis.
- Recommendation #15: DBHDS, DMAS and VDH will work with the VAAP and Virginia Academy of Family Physicians (VAFP) Association to increase the periodic use of regular standardized developmental screening tools for all developmental delays, including autism.

- *Recommendation #19:* DBHDS should seek emergency regulatory authority to include Intensive Individual Support Services as a new licensed provider category.
- *Recommendation #23:* Expand Department of Rehabilitative Services (DRS) case services to respond to the increasing demand for ASD services.
- *Recommendation #26:* Implement five (5) five-day, regional Autism Work Support trainings for a total of 750 participants, designed to increase the knowledge base of employment service providers, day support providers, individuals with ASD and their family members about work supports for persons with ASD.

Continue to Promote Awareness about ASDs and Provide Information to Families

As DBHDS developed this report and worked with families and other stakeholders, it underscored the importance of continuing to promote awareness about ASDs and resources available to families. DBHDS and other state agencies must play an important role in ensuring that there is reliable and up-to-date information available to families regarding supports and services for their loved ones.

- *Recommendation #11:* DBHDS will work with other state agencies to seek grant funding to establish a statewide public service campaign regarding early detection and screening for autism.
- *Recommendation #12:* DBHDS will work with other state agencies to increase the capacity for screening for ASDs in a non-clinical setting, such as local Departments of Social Services, day care centers, Head Start/Early Head Start and other places that come into contact with young children.
- *Recommendation #16:* The State Part C Program should modify its data collection to track progress measures by disability, including ASDs. The State Part C Program should also collect specific disability information as part of its routine family surveys.
- *Recommendation #27:* Create a MicroBoard Association for Virginia to assist adults with developmental disabilities to live independently using natural supports within their home communities.
- *Recommendation #28:* ASD Training developed by the Public Safety Workgroup should be recognized as the minimum training standard in the Commonwealth of Virginia for all public safety personnel.
- *Recommendation #29:* All public safety personnel (including judges, magistrates, attorneys, law enforcement, fire/EMS, etc.) should receive basic autism awareness training (developed by the PSW) to understand characteristics of autism.
- *Recommendation #30:* The General Assembly should require all public safety personnel to receive ongoing in-service training for a more in-depth understanding and awareness of

autism spectrum disorders, including current strategies and interventions to use during an encounter with an individual with autism.

- *Recommendation#31*: The General Assembly should provide a pool of funds for public service agencies to access when they are unable to pay for ASD awareness training.

Action Plan

Based on the input of collaborating state agencies, stakeholder input, and the public comments received, DBHDS proposes the following action plan to address the recommendations in this report.

FY2012		
Recommendation	Estimated Cost	Status
The General Assembly should adopt a single definition of developmental disabilities in Virginia.	\$0	Requires General Assembly action
Move the day to day administration of the IFDDS waiver from DMAS to DBHDS, in order to realign and increase coordination of the ID and IFDDS waiver programs for families.	\$0	Requires General Assembly action
DMAS and DBHDS to convene a work group to study the costs and parameters of combining the ID and IFDDS Waivers into one comprehensive waiver DD Waiver.	\$0	Approval of the merger of the waivers would require General Assembly action during 2012 session after completion of study and identification of costs
In determining appropriate strategies for addressing the treatment needs of children with ASDs, Virginia should continue to examine the role of private insurance in covering treatment.	Varies	Requires General Assembly action
Continue funding of the Virginia Autism Council through DBHDS for Council operations and tuition reimbursement for non-public education professionals and providers.	\$75,000	Requires General Assembly action
DBHDS should seek emergency regulatory authority to include Intensive Individual Support Services as a new license provider category.	\$0	Requires General Assembly action
DBHDS with RRTC will implement five (5) five-day, regional Autism Work Support trainings for a total of 750 participants, designed to increase the knowledge base of employment service providers, day support providers, individuals with ASD and their family members about work supports for persons with ASD	\$150,000	Requires General Assembly action

ASD Training developed by the Public Safety Workgroup (PSW) should be recognized as the minimum training standard in the Commonwealth of Virginia for all public safety personnel. All public safety personnel (including judges, magistrates, attorneys, law enforcement, fire/EMS, etc.) should receive basic autism awareness (developed by the PSW) training to understand characteristics of autism. The General Assembly should provide a pool of funds for public service agencies to access when they are unable to pay for ASD awareness training.	\$95,000	Requires General Assembly action
Promote the professional development of educators in the area of ASD expertise by creating online coursework that will result in achieving certification as a Board Certified Behavior Analyst (BCBA) or a Board Certified Assistant Behavior Analyst (BCaBA).	\$750,000	Requires General Assembly action
DBHDS, DMAS and VDH will work with the VAAP and Virginia Academy of Family Physicians (VAFP) Association to increase the periodic use of regular standardized developmental screening tools for all developmental delays, including autism.	\$0	DBHDS will initiate with DMAS, VDH, V-APP, and VAFP
DBHDS will work with other state agencies to increase the capacity for screening for ASD in a non-clinical setting, such as local Departments of Social Services, day care centers, Head Start/Early Head Start and other places that come into contact with young children.	\$0	DBHDS will initiate with other state agencies in FY12
The State Part C Program should modify its data collection to track progress measures by disability, including ASDs. The State Part C Program should also collect specific disability information as part of its routine family surveys.	TBD	Begin FY12
DBHDS will work with stakeholders to create a MicroBoard Association for Virginia to assist adults with developmental disabilities to live independently using natural supports within their home communities.	\$150,000	Begin FY12
The State Part C Program and DOE Part B Programs should study the costs and benefits of providing more specialized programs for children with ASDs that includes more intense services, staffing, and structure.	\$0	DBHDS will initiate with DOE in FY12
DBHDS and DMAS should determine the level of need and associated cost of a Medicaid respite waiver to provide minimum services to children with developmental disabilities who meet waiver level of functioning criteria.	\$0	DBHDS will initiate with DMAS in FY12
The State Infant & Toddler Connection Program will finalize "Service Guidelines for Providing Early Intervention Services to Infants and Toddlers with ASDs," by June 2011.	\$0	Ongoing

ASD Training developed by the Public Safety Workgroup should be recognized as the minimum training standard in the Commonwealth of Virginia for all public safety personnel.	\$0	
The General Assembly should require all public safety personnel to receive ongoing in-service training for a more in-depth understanding and awareness of autism spectrum disorders, including current strategies and interventions to use during an encounter with an individual with autism.	\$95,000	
The State Infant & Toddler Connection Program will collaborate with the Virginia Chapter of the American Academy of Pediatrics to increase pediatrician knowledge base of how and where to refer families for full team diagnosis.	\$0	Ongoing
Expand and develop Communities of Practice in Autism (CoPA) in order to develop skills and enhance service delivery planning/implementation through Part C Early Intervention.	\$516,000	Ongoing
DBHDS will work with other state agencies to seek grant funding to establish a statewide public service campaign regarding early detection and screening for autism.	\$0	Ongoing
FY2013		
Recommendation	Estimated Cost	Status
Approve merger of IFDDS and ID waiver programs into one comprehensive DD waiver	TBD	Requires General Assembly action
Establish CSB's as the single point of entry for case management and information and referral in the Developmental Disability System, including serving individuals with ASDs.	\$800,000	Requires General Assembly action
Expand existing VDH medical homes initiative to assist physicians in creating medical homes for children with autism or other special needs.	\$470,000	Requires General Assembly action
Expand DRS case services to respond to the increasing demand for ASD services.	\$1,000,000	Requires General Assembly action
Increase access to employment supports for up to 200 individuals with autism through the long-term employment supports of the LTESS program.	\$600,000	Requires General Assembly action
Increase employment skills and opportunities for adults with ASD no longer in the school system, through a dual phase Project SEARCH model.	\$500,000	Requires General Assembly action
Increase by 50 the number of individuals trained and certified as Positive Behavior Supports Facilitators.	\$112,000	Requires General Assembly action

The General Assembly should provide a pool of funds for public service agencies to access when they are unable to pay for ASD awareness training.	\$10,000	
All public safety personnel (including judges, magistrates, attorneys, law enforcement, fire/EMS, etc.) should receive basic autism awareness training (developed by the PSW) to understand characteristics of autism.	\$0	Cost included in the comprehensive public safety training above
Develop an on-line training program and expand the DBHDS-community college certificate program for direct support professionals to promote a well qualified DD community-based workforce.	TBD	DBHDS will initiate in FY12 and complete in FY13
FY2014		
Recommendation	Estimated Cost	Status
Increase grants to localities to be used by the Community Services Boards/Behavioral Health Authorities as Family and Individual Support funds as needed for individuals who are not currently receiving or are ineligible for services under the ID or IFDDS waivers.	\$5,000,000	Requires General Assembly action

Appendix A

Summary of JLARC Recommendations from *Assessment of Services for Virginians with Autism Spectrum Disorders* (House Document No. 8, 2009)

<p>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.</p>
<p>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.</p>
<p>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.</p>
<p>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.</p>
<p>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.</p>
<p>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.</p>
<p>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.</p>

<p>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.</p>
<p>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.</p>
<p>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.</p>
<p>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.</p>
<p>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.</p>
<p>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.</p>
<p>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.</p>
<p>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.</p>
<p>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.</p>
<p>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.</p>

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 B

Glossary

Applied Behavior Analysis (ABA) – a scientific approach to understanding socially significant behavior, how behavior works and how learning takes place. By analyzing the environment, trained professionals are able to determine certain triggers or events that may be causing the behavior to occur. With this information, it is more likely that an intervention can be designed to help change that behavior. ABA is the use of techniques and principles such as reinforcement, to address socially important problems and to bring about meaningful behavior change. Research documents that many ABA techniques are effective for building skills of all kinds for children, adolescents, and adults with autism. ABA methods are useful for helping individuals and families manage some challenging behaviors.

Asperger’s Syndrome – one of the Autism Spectrum Disorders characterized by qualitative impairment in social interaction, by stereotyped and restricted patterns of behavior, activities and interests, and by no clinically significant delay in cognitive development or general delay in language

Board Certified Behavior Analysts (BCBA) - practitioners who conduct descriptive and systematic behavioral assessments, including functional analyses, and provide behavior analytic interpretations of the results. BCBAs design and supervise behavior analytic interventions, develop and implement appropriate assessment and intervention methods, teach others to carry out ethical and effective behavior analytic interventions based on published research and design and deliver instruction in behavior analysis. BCBAs supervise the work of Board Certified Assistant Behavior Analysts and others who implement behavior analytic interventions.

Board Certified Assistant Behavior Analysts (BCaBA) – practitioners who conduct descriptive behavioral assessments, interpret the results and design ethical and effective behavior analytic interventions for individuals. The BCaBA designs and oversees interventions in familiar cases that are consistent with the dimensions of applied behavior analysis and obtains technical direction from a BCBA for unfamiliar situations. The BCaBA teaches others to carry out interventions and may assist a BCBA with the design and delivery of introductory level instruction in behavior analysis. Each BCaBA must practice under the supervision of a BCBA.

Community Services Board (CSB)/Behavioral Health Authority (BHA) – the local agency, established by a city or county or combination of counties or cities under Chapter 5 (§ 37.2-500 et seq.) (CSB) or Chapter 1 (§ 37.2-100) (BHA) of Title 37.2 of the Code of Virginia that plans, provides, and evaluates mental health, intellectual disability and substance abuse services in the jurisdiction or jurisdictions it serves.

Early Intervention – is a federally mandated system of supports and services for infants and toddlers with developmental delays and disabilities, birth to age three, and their families. This system operates under the Individuals with Disabilities Education Act. The steps in early

intervention are referral for evaluation and assessment, screening, evaluation and assessment, Individualized Family Service Plan (IFSP), IFSP implementation and transition.

Employment Service Organizations – a network of community rehabilitation agencies that provide employment and vocational services throughout the state in partnership with the Department of Rehabilitative Services.

Family and Individual Supports – Virginia General Fund dollars available to individuals with disabilities and their families to meet disability-related needs not covered by other funding sources (such as respite or employment services for those ineligible for Medicaid Waivers).

Individuals with Disabilities Education Act (IDEA) – federal legislation first passed in 1975 as P.L. 94-142 (The Education of All Handicapped Children Act), reauthorized in 1997, as IDEA (P.L. 105-17) and reauthorized once more in 2004 as the Individuals with Disabilities Education Improvement Act (P.L. 108-446; 20 USC §1400 *et seq.*), also commonly referred to as IDEA 2004. IDEA currently mandates a free appropriate public education (FAPE) for all children with disabilities 3 to 21 years of age (Part B) and includes Part C for children from birth to age three.

Individualized Family Service Plan (IFSP) – a written plan for providing early intervention supports and services to a Part C eligible child and his or her family. This is one of the requirements of early intervention services.

Individual Resource Allocation – a method of linking resource allocation amounts to individual needs. This may be performed either by linking individual assessment data to the costs of services for individuals with similar needs or a payment allocation set through a person-centered planning process in which provider rates are based on statewide tiers or a series of levels reflecting individual need differences.

Integrated Employment – employment for individuals with developmental disabilities in regular jobs in the community where they earn at least minimum wage and have opportunities to interact with people who do not have disabilities. Integrated employment is often achieved through job find and on-the-job training conducted by a supported employment job coach.

Intellectual Disability – a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.

Level of Functioning Survey – the functional eligibility determining tool for the Intellectual Disability Waiver and the Individual and Family Developmental Disability Waiver.

Medicaid State Plan Services – that portion of Medicaid funded services that are available to any individual who qualifies for Medicaid based on income and resource criteria. These include, but are not limited to inpatient and outpatient hospital services, emergency hospital services, physician and nurse midwife services, federally qualified health centers and rural health clinic services, laboratories and x-ray services, transportation services, family planning services and supplies, nursing facility services, home health services, and Early and Periodic Screening, Diagnosis, and Treatment program for children (“EPSDT”).

Part B – that section of the federal IDEA legislation which assures that children with disabilities from 3 – 21 years of age “have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.”

Part C – the portion of the Individuals with Disabilities Education Act that provides incentives to states to make available services to children from birth to three years of age. It is also known as “Programs for Infants and Toddlers with Disabilities.” Federal Part C regulations require that a statewide system of early intervention services and state policy are in effect to ensure that the appropriate early intervention supports and services are available to all infants and toddlers with disabilities and/or developmental delay and their families. In Virginia, the Part C system is called “Infant & Toddler Connection of Virginia.” The state lead agency is the Department of Behavioral Health and Developmental Services.

Person-Centered Planning – a process for learning how a person wants to live and what is important to him or her in everyday life. Person-centered planning helps the individual plan for positive outcomes with the help of people who care about the individual. Those involved in the process must really listen to the person and the people who know the individual best, in order to learn what is important to and for the individual and translating a vision for a better or different life into action plans.

Positive Behavior Supports – is a comprehensive approach to behavior change that combines principles and practices from applied behavior analysis, the inclusion and self-determination movements, and person-centered planning and values. It is a research-based approach that teaches people with challenging behaviors, and the people who support them, new skills that promote successful living in community settings with the primary goal of improving the quality of life of individuals with challenges, while reducing or eliminating problem behaviors.

Single Point of Entry – a single agency for each particular region/locality that performs an information and referral role and as such is tasked with gathering basic information about the individual seeking services, conducting an initial screening/assessment to determine the individual’s general needs and eligibility for various programs of support and collecting/reporting data on the needs of individuals in order to assist the state and locality with future planning and budgeting for services.

Supports Intensity Scale (SIS) – a tool developed by AAIDD used to measure an individual’s frequency of support needs across life activities, behaviors and medical needs. It was developed to be used to assist in individual support planning for individuals with intellectual and other developmental disabilities.

Targeted Case Management (also known as Support Coordination) – Optional state plan services that are furnished to assist qualifying Medicaid individuals to gain access to and continue to receive needed social, residential, vocational, educational, medical and other services.

Training and Technical Assistance Centers (T/TAC) – funded by the Virginia Department of Education and linked to universities around the Commonwealth, these eight regional centers comprise a statewide system emphasizing collaboration in the planning and provision of services to meet state and local staff development needs in order to improve educational opportunities and contribute to the success of children and youth with disabilities (birth - 22 years). The centers provide training and technical assistance in order to increase the capacity of schools, school personnel, service providers and families to meet the needs of children and youth..

Transition-aged – youth with disabilities between the ages of 14 and 22 who are preparing to move from supports provided by the educational system to the adult service system and/or the world of adults without disabilities.

Appendix C

Workgroups and Stakeholders

Workgroup	Stakeholders	
DBHDS		
Diagnosis and Assessment	Brian Campbell	Department of Medical Assistance Services/Early Periodic Screening Diagnosis and Treatment
	Carol Burke	Part C – Infant Toddler Connection - Rockbridge
	Deana Buck	Partnership for People with Developmental Disabilities
	John Harrington, MD	Parent – Virginia Beach/ Virginia Chapter American Academy of Pediatrics
	Holly Jenkins	Parent- Henrico/ Autism Society of America Central Virginia Chapter
	Jessica Philips	Commonwealth Autism Service
	Karen Waters	Part C – Infant Toddler Connection – Chesterfield County
	Mitchell Blair	Community Service Board - Fairfax
	Paul Durbin-Westby	Self Advocate – Louisa County
	Karen Poe	Southwestern Virginia Training Center
	Joanne Boise	Virginia Department of Health
	Mary Ann Discenza	Department of Behavioral Health and Developmental Services /Part C
Cindy Gwinn	Department of Behavioral Health and Developmental Services/ Office of Developmental Services/Parent	
Resources	Jan Markin	Parent – Chesterfield County
	Jim Gillespie	Rappahannock Area Community Services Board
	Joanna Bryant	Parent - Virginia Beach/Autism Society of America Tidewater Chapter
	Katherine Lawson	Virginia Board for People with Disabilities
	Sally Kirchoff	Parent –Chesterfield County
	Wendy Turner	Parent –Henrico County
	Richard Kriner	Department of Rehabilitative Services
	Cindy Gwinn	Department of Behavioral Health and Developmental Services/ Office of Developmental Services/Parent
	John Toscano	Commonwealth Autism Service
Adulthood	Ronald Alf	Parent -Fairfax
	Judy Bailey	Provider-employment services
	Sheila Billingsley	Parent - Arlington
	Kim Lett	Parent – Stafford County/Center for Independent

		Living- Fredericksburg
	Bradford Hulcher	Parent – Henrico County/ Autism Society of America
	Richard Kriner	Department of Rehabilitative Services
	Heidi Lawyer	Virginia Board for People with Disabilities
	Joan Lipstock	Parent – Henrico county
	Ann Long	Career & Transition Services
	Karen McCormick	Parent – Harrisonburg/ Shenandoah Valley Autism Partnership
	Linda Moore	Parent – Hanover County
	Dottie Narodny	Commonwealth Autism Service
	Lisa Poe	Richmond Residential Services
	Kimberli Russ Vida	Teacher - Richmond
	Bob Villa	Powhatan/Goochland Community Services Board
	Woody Witt	Parent – Fairfax County/ Community Services Board Member
	Dana Yarbrough	Partnership for People with Developmental Disabilities / Parent
Statewide Accountability/ Single Point of Entry	Ron Alf	Parent- Fairfax
	Steve Ankiel	Department of Medical Assistant Services
	Pat Bennett	Parent -Vienna
	Mary Ann Bergeron	Virginia Association of Community Services Boards
	Ron Branscome	Rappahannock Area Community Service Board
	George Braunstien	Fairfax/Falls Church Community Services Board
	Debbie Burcham	Chesterfield Community Services Board
	Tim Capoldo	Norfolk Community Services Board
	Mary Cole	Cumberland Mountain Community Services Board
	Mark Diorio	Northern Virginia Training Center
	Jill Egle	The Arc of Northern Virginia/ self advocate
	Deb Fulz	DisAbility Resource Center - Fredericksburg
	Diane Gallegos	Henrico Community Services Board
	Jim Gillespie	Rappahannock Area Community Services Board
	Cindy Gwinn	Department of Behavioral Health and Developmental Services/ Office of Developmental Services/Parent
	Lucia Harrigan	Hampton-Newport News Community Services Board
	Emily Helmboldt	Department of Behavioral Health and Developmental Services / Office of Developmental Services
	Maureen Hollowell	Centers for Independent Living -Virginia Beach
	Bradford Hulcher	Parent – Henrico County/ Autism Society of America Central Virginia Chapter
	Jill Jacobs	Parent – Woodbridge/Provider Ability Unleashed Developmental Disabilities Case Manager
Stephen King	Autumn Home –Developmental Disability Case Manager	
Marisa Laois	Self Advocate	
Heidi Lawyer	Virginia Board for People with Disabilities	

Jay Lazier	Virginia Beach Community Services Board
Helen Leonard	Department of Medical Assistance Services
Jamie Liban	The Arc of Virginia
Carol McCarthy	Hampton-Newport News Community Services Board
Brian Miller	Prince William County Community Services Board
Tracy Nordin	Parent - Alexandria /Provider - Access and Inclusion Developmental Disabilities Case Manager
Mike O'Conner	Henrico County Community Services Board
Lee Price	Department of Behavioral Health and Developmental Services / Office of Developmental Services
Linda Redmond	Virginia Board for People with Disabilities
Carol Schall	Virginia Autism Resource Center
Betty Thompson	Parent – Chesterfield County
Dawn Traver	Department of Behavioral Health and Developmental Services / Office of Developmental Services
Josh Wilson	Self Advocate
Woody Witt	Parent- Fairfax
Alan Wooten	Fairfax/Falls Church Community Services Board
Tera Yoder	Partnership for People with Developmental Disabilities
Didi Zaryczny	Parent – Bedford/ Commonwealth Autism Service

Review of Agency March 31, 2010 Reports

Alan Wooten	Fairfax/Falls Church Community Services Board
Alison Standing	Part C Infant Toddler Connection - Rappahannock Area Community Services Board
Beth Tetrault	Henrico County Community Services Board
Bill Hawkins	Southeastern Virginia Training Center
Bill Painter	RRMM Architects
Bob Villa	Goochland/Powhatan Community Services Board
Bradford Hulcher	Parent – Henrico County/ Autism Society of America Central Virginia Chapter
Brian Miller	Prince William County Community Services Board
Carol Webster	District 19 Community Services Board
Cathy Healy	Parent Educational Advocacy Training Center
Courtney Phillips	Rappahannock- Rapidan Community Services Board
Cynthia McKoy	Central Fairfax Services
Cynthia Smith	Department of Behavioral Health and Developmental Services/ Office of Developmental Services

	Dan Longo	Colonial Behavioral Health
	Dana Yarborough	Partnership for People with Developmental Disabilities / Parent
	Darlene Rawls	Western Tidewater Community Services Board
	Deborah Roundtree	Estelle Place LLC
	Debra Smith	Crossroads Community Services Board
	Dennis Pancoe	Arc of Piedmont
	Elaine Senft	Northern Virginia Training Center
	Gail Rheinheimer	Department of Behavioral Health and Developmental Services/ Office of Developmental Services
	Glорidine Lambert	New Beginnings, Inc.
	Greg Preston	Piedmont Community Services Board
	Jack Brandt	Self Advocate/ Partnership for People with Developmental Disabilities
	Jamie Liban	The Arc of Virginia
	Jessica Philips	Commonwealth Autism Services
	John Toscano	Commonwealth Autism Services
	Joward Olshansky	Arc of Piedmont
	Karen Telelski	VaACCSES
	LaBrenda Haynes	Destiny Place LLC
	Lisa Madron	Prince William Community Services Board
	Lynn McCrobie	Middle Peninsula/Northern Neck Community Services Board
	Pat Rimwell	Southeastern Virginia Training Center
	Ron Wallace	River City Residences, LLC
	Samantha Marsh	Virginia Department of Education
	Sarah Luck	Richmond Residential Services
	Traci Roberson	Central Virginia Community Services Board
	Vernessa Samuel	Arc of North Central Virginia

Public Safety

	B. Leigh Drewry, Jr.	Cunningham and Drewry
	Bryan Lawrence	Roanoke City Police Department
	Caroline E. Kirkpatrick	Virginia Supreme Court
	Dana Schrad	Virginia Association of Chiefs of Police
	David Jolly	Virginia Department of Fire programs
	Didi Zaryczny	Commonwealth Autism Service
	Don Hansen	Virginia Department of Fire Programs
	Donna Michaelis	Virginia Department of Criminal Justice Services
	Gary Brown	Virginia Offices of EMS/Virginia Department of Health
	Greg Neiman	Virginia Office of EMS /Virginia Department of Health

	Linda Caldwell	Parent
	Mark Eggeman	Virginia Department of Emergency Management
	Ronald E. Bessent	Virginia Department of Criminal Justice Services
	Ronald J. Staton	Central Virginia Training Academy
	Ronnie Sitler	Lynchburg Police Department
	Sheriff Charles Phelps	Virginia Sheriff's Association
	Sheriff Charlie Jett	Virginia Sheriff's Association
	Shirl Light	Parent
	Sylvester Henderson	Richmond Firefighter/Parent
	Tim W. Sutton	Hanover County Sheriff's Office
	Tommy Carter	Project Lifesaver International
	Travis Akins	Roanoke City Police Department
	W.G. Shelton, Jr.	Virginia Department of Fire Programs

Appendix D

Commonwealth Autism Services Facilitated Autism Action Groups

Central Virginia Autism Action Group (CVAAG)

Covers: Counties of Amherst, Bedford, Appomattox and Campbell, and including the Cities of Lynchburg and Bedford

Charlottesville Region Autism Action Group (CRAAG). This Autism Action Group will bring together representatives from the area served by the Region 10 Community Services Board. This includes the counties/cities of Albemarle, Crozet, Earlysville, Esmont, Greenwood, Keswick, North Garden, Scottsville, White Hall, Charlottesville, Fluvanna, Kents Store, Palmyra, Dyke, Graves Mill, Greene, Ruckersville, Stanardsville, Bumpass, Louisa, Mineral, Trevilians, Afton, Arrington, Colleen, Faber, Gladstone, Love, Lovingston, Massies Mill, Montebello, Nellysford, Nelson, Piney River, Roseland, Schuyler, Shipman, Tyro, Wingina, and Wintergreen.

Fredericksburg Regional Autism Action Group (FRAAG)

Covers: All entities within the Counties of Stafford, Spotsylvania, King George and Caroline, including the City of Fredericksburg.

Greater Roanoke Valley Autism Action Group (GRVAAG)

Covers: All entities within Botetourt, Craig, Roanoke and Franklin Counties, including the Cities of Salem, Roanoke and Rocky Mount

New River Valley Autism Action Group (NRVAAG)

Covers: All entities within Giles, Montgomery, Pulaski and Floyd, including the Cities of Blacksburg, Christiansburg, Pulaski and Radford.

Piedmont Autism Action Group (PAAG)

Covers: All entities within the Counties of Patrick and Henry, including the City of Martinsville.

Rappahannock/Rapidan Autism Action Group (RRAAG)

Covers: All entities within the Counties of Rappahannock, Fauquier, Culpeper, Madison and Orange.

Southwest Virginia Autism Action Group (SWVAAG)

Covers: All entities within Lee, Scott, Wise, Dickenson, Russell, Washington, Buchanan, Tazewell, Smyth, Grayson, Bland, Wythe and Carroll Counties.

Appendix E

Public Comment from TACIDD Meeting October 15, 2010

Blue = People really like this idea
Green = People are OK with this idea
Red = People are opposed to this idea

JLARC STUDY RECOMMENDATIONS	Blue	Green	Red
RECOMMENDATION #1: Adopt a single definition of Developmental Disabilities in Virginia	10	2	1
A. For adopting federal definition insuring that: if it is a developmental disability diagnosed after 22 they would be eligible	7	4	0
B. Edit – Move to lower priority, reform at each recommendation			5
C. Caution about changing the definition from the Federal Government definition. - Need to define who makes the determination, psychologist, physical/medical doctor, etc. - What tool(s) are used to determine someone meets the definition			
D. While this is an ASD Report, the state is adopting a broader definition of developmental disabilities. As a result, individuals with CP, spina bifida, head injury & epilepsy <u>also</u> have service needs.	1		
E. What happens to people with cerebral palsy, muscular dystrophy, multiple sclerosis and others now eligible for IFDDS waiver?	2		
RECOMMENDATION #2: Establish community services boards as the single point of entry for the Developmental Disability system, including serving individuals with ASD.		14	9
A. Single point of entry for data collection but choice of private or public providers.		2	2

JLARC STUDY RECOMMENDATIONS	Blue	Green	Red
C. Research bringing EDCD to more individuals; open up criteria. <ul style="list-style-type: none"> - Research bringin EDCD under the DBHDS roof to continue to bring more resources to individuals. - Could DD waivers/ID waiver/ECDC Waiver be rolled into one waiver to address the issue of licensure to all. More programs to serve this waiver. Have different levels to the waiver. 	2	1	
D. Moving the day-to-day of a combined waiver. Now currently as two separate waivers.	2		1
RECOMMENDATION #4: Create a stakeholder workgroup to determine the parameters and costs associated with combining the ID and IFDDDS Waivers into one comprehensive DD Waiver. The workgroup would address merging of the waiver wait lists, establish parameters for case management, determine the costs associated with offering residential and congregate supports to a larger population, and the feasibility of implementing an Individual Resource Allocation methodology to waiver services, in order to present its findings to the General Assembly for the 2010 budget session.	1		2
A. Totally change, bringing in outside group/entity. <ul style="list-style-type: none"> - Ensuring there are stakeholders. 	1		
B. Stakeholder should consist of a 1:1 ratio of government agency representatives to consumers and families.			
C. Fifty-one percent of stakeholder group should be made up of family members and self-advocates. <ul style="list-style-type: none"> - Needs to include the recommendations /dialogue consensus of the workgroup as the backdrop for the recommendation. 	2		
D. Clarify the role of CSB contracting with private case managers. Auditors should audit private case managers directly.	1		
E. Creating stakeholders group <ul style="list-style-type: none"> - Need to also look at waiting lists. - Make sure family members are well represented. - Have a legislative representative on group. - Need to make a mandate to get rid of the waiting lists. - Mandate funding so we don't have to beg every year. 	31		
F. Eliminate the use of the term "waitlist" instead use terms such as "system capacity" and "gap in capacity" or "lack of	1		1

JLARC STUDY RECOMMENDATIONS	Blue	Green	Red
capacity.” Wait listing implies that an individual “waitlisted” will be served. It is a false assumption given to families. We need to focus on the system’s capacity – not families waiting. The change in terms will provide a better focus of the gap between those and those <u>not</u> served.			
RECOMMENDATION #5: Increase grants to localities to be used by the community service board as family and individual support funds as needed with a limit of up to \$1,500 per recipient per year.	2	1	8
A. Needs to be better defined; Money for Individuals.	6	3	
B. Strike CSB 9; use independent single point of entry.			
C. Grant (what will be the \$1,500 money be spent for) why is it important? Build on criteria. <ul style="list-style-type: none"> - What is the amount now? - Were helpful – reinstate - What is it for? - Non-waiver 	3		
D. Add language – insure that use of funds is restricted to family and individual support. <ul style="list-style-type: none"> - Add fully funded – commit to a significant investment - Add develop other mechanisms beyond this fund to provide family-to-family support. 	3		
E. \$1,500 would be used for families to start a person case trust. <ul style="list-style-type: none"> - Use this to start (look at creating this for families) a 529 for individuals with disabilities. Create this similar to the VCEP college education program. 	4	1	
F. Amount of Family Support Fund amount needs to be variable – based on mean cost of living in the community-region rather than one fixed statewide rate of \$2,500.	1		
RECOMMENDATION #6: Develop an on-line training program and expand the DBHDS Community College Certificate program for direct support professionals to promote a well qualified DD community-based workforce.	3	1	12
A. Utilize existing adopt programs that exist, create a suite of training opportunities. Not just online.	9	2	
B. Expand on-line program with hands on component. Also expand community college certificate program for direct support professionals in conjunction with VCU.			

JLARC STUDY RECOMMENDATIONS	Blue	Green	Red
C. Include job embedded training (coaching) and endure implementation of best practices.	1		
D. Utilize private non-profit schools such as the Virginia Institute of Autism or Faison School to provide training lab for ABA therapists and BCBA consultants. Hands-on training and supervision is critical. ABA schools have applied knowledge over many years and children to observe and interact with during training.	2		
E. Make attending training a reimbursable activity up to a reasonable amount of hours.			
F. Open training to more than line staff, open to case managers and supervisors. - Who funds this training? - Recommend funding from state to provide this training.	2		
G. Refrain from forcing providers to purchase services, training or certifications from a single vendor. - CDS - ABA - CARF			
RECOMMENDATION #7: Expand and develop Communities of Practice in Autism (COPA) in order to develop skills and enhance service delivery planning/implementation through Part C Early Intervention.	12	6	
A. We must increase access to intensive in-home EI services to provide 20+ hours per week. - Ensure services for children who are not Medicaid eligible - Clarify goal to increase through a variety of strategies.	1		
RECOMMENDATION #8: Expand VDH VISP grant to 15 additional sites to provide assistance to physicians in creating medical homes for children with Autism and all children with special needs.	8	4	
A. More than 15 sites	3	4	
RECOMMENDATION #9: Seek grant seeking to establish a statewide public service campaign regarding early detection and screening for autism.	2	3	
A. Don't recreate the wheel. Expand what is out there.	3	4	

JLARC STUDY RECOMMENDATIONS	Blue	Green	Red
B. Increase visibility of state benefits to special needs families.			
RECOMMENDATION #10: Increase the capacity for screening for ASD in a non-clinical setting such as local Departments of Social Services, day care centers, Head Start/Early Head Start and other places that come into contact with young children.	1		8
A. Increase capacity for screening by...ensuring this group knows the signs and are able to direct parents to appropriate resources. Clarify language.		5	
B. Increase access to timely follow-up evaluation upon positive screening.	2	3	
RECOMMENDATION #11: Increase by 50 the number of individuals trained and endorsed as Positive Behavior Supports Facilitators.	11	4	2
A. Increase funding	3		
B. Require on-going supervision and education to the extent possible spread this increased capacity across the state - Consider combining PBS facilitation and BCBA certification as there is consistent qualifications			2
C. Agree that service providers could use more direction regarding training and workforce development - Recommend the Department providing core competencies to all applicable training so consistent training can be developed at the agency level. - If an agency is mandated to obtain training or certification from the outside, then additional funds would have to be included to pay the provider for this added expense. - An unfunded mandate would surely diminish the capacity of both private and public sector service providers.			
RECOMMENDATION #12: Determine the level of need and associated cost of a Medicaid respite waiver to provide minimum services to children with ASDs who meet waiver level of functioning criteria.			29
A. Why another Waiver? Fix EDCD. Broader definitions = everybody on waitlist.	2	2	

JLARC STUDY RECOMMENDATIONS	Blue	Green	Red
B. Expand individual /family support funds from \$1,500 per year to \$5,000 per year. <ul style="list-style-type: none"> - Implement the plan for elimination of ID/DD waiver wait list with elimination of waitlist by 2018-2020 biennium. Include 400 ID and 67 DD Waiver in Medicaid J & I each year. 	23	1	
C. Applications for the EDCD waiver should be ASD focused.	1		3
D. Respite does not need to be a single waiver. Respite should be provided as well as an appropriate away of services that are identified as a need in all waivers.		2	
E. Eliminate 5% in HCBS services and restore respite in services in HCBS Waivers! (cut from 720 to 240 year.)			
RECOMMENDATION #13: In determining appropriate strategies for addressing the treatment needs of children with ASDs, Virginia should continue to examine the role of private insurance in covering treatment.	5	1	4
A. Mandate private insurance/proven medical treatments	21	3	
B. Strike “continue to examine” and replace with “mandate” private insurance in covering treatment. In determining strategies for addressing the treatment needs of child with ASDs, Virginia will define autism (<i>biologically based mental illness – the group didn’t mean for this to be there – it was part of discussion</i>) as an illness that benefits from treatment. Children and adults with ASD benefit from evidence based best practice therapies, specially speech therapy, occupational therapy, physical therapy and behavior therapies like ABA and DIR floor time. Required private insurance companies should be to cover these and other medically necessary interventions.	6		7
C. Autism is a medical issue/condition should be insured. EXAMPLE – Loudoun 11150 = Autism 1110 = Autism <ul style="list-style-type: none"> - Phase in by age - Coverage for non-Medicaid 	1	1	
D. Needs Data <ul style="list-style-type: none"> - Address prevention of later - Greater costs 			
RECOMMENDATION #14: Create online courses that will promote the certification of educators as Board Certified Analyst (BCBA) or a Board Certified Assistance Behavior	5	1	2

JLARC STUDY RECOMMENDATIONS	Blue	Green	Red
Analyst (BcaBA)			
A. Utilize what already exists and expand on a variety		4	
B. Add: Create a number of sites for supervision that will result in quality/skilled practitioners (ensure there are a variety of sites to address)			
C. Training and core competencies <ul style="list-style-type: none"> - “Deemed” status of CARF Accreditation in services provided. Should qualify a provider. 			
RECOMMENDATION #15: Expand DRS case services to respond to the increasing demand for ASD services.	1		3
A. Enable access to work incentives benefits, counseling work world software and the Medicaid work program.	4	2	
B. Combine # 15 – Does not describe problem Combine #17 – Identify measurable solution Combine #19 – Cost & phase in			
C. Infuse state general funds to build capacity and expand DRS case services for individuals with ASD	4	4	
RECOMMENDATION #16: Establish 5 ASD specialty caseload counselor positions for DRS in parts of the Commonwealth with high numbers of individuals with ASD.	2	1	11
A. Considerably expand across the state, not just areas with high numbers of ASD.	7	2	
B. Ensure that the specialist case workers (DRS counselors) have some charge to provide a level of consultation to DRS counselors in other regions.	4		
C. This is an ineffective strategy <ul style="list-style-type: none"> - This does not support the direct services system – the individual receiving the services. - It does not provide or address the sustaining service needs of the individual. - DRS is short-term. This is a very costly strategy that does not build service system capacity. 	2		
RECOMMENDATION #17: Expand employment supports for up to 200 individuals with autism through the long-term employment supports of the LTESS program.	1	6	8
A. Re-evaluate and redistribute in a more equitable way. Incorporate state use into current vocational options to expand competitive employment.		1	
B. A state set aside program that mirrors the federal ability one	14	2	

JLARC STUDY RECOMMENDATIONS	Blue	Green	Red
(JWOD) program. More than 20 states have such a program. Both federal and state set aside programs have created tens of thousands of jobs for people with disabilities.			
C. Too much money into public system versus building system capacity of private sector. DRS won ten year study. (Dr. David Green – University of Virginia says “every \$1 – get \$3.55 back when they use privates.”	3		1
D. Arbitrary number of 200 individuals average current cost is \$1,500-2,000 for competitive community-based employment. These funds have been cut \$1.25 million over last two years because they are general fund dollars. Current need (without previous cut) is \$850K - \$1 million. (Folks already in pipeline.)			
RECOMMENDATION #18: Increase employment skills and opportunities for adults with ASD no longer in school system, through a dual phase Project SEARCH Model.	3	5	
A. And add models.	8	3	
B. Increase employment skills and opportunities for adults with ASD no longer in the school system through Project SEARCH and offer best practice employment models.	3	1	
RECOMMENDATION #19: Implement five (5) five-day, regional Autism Work Support trainings for a total of 750 participants, designed to increase the knowledge base of employment service providers, day support providers, individuals with ASD and their family members about work supports for persons with ASD.	1	5	
A. Creative alternatives for collaborations in the community, not just in the state system.	1		
RECOMMENDATION #20: Provide resources to CSBs to create a limited number of micro boards to directly assist families dealing with ASDs.			6
A. Provide funding for the development of a micro board network.	10	5	
B. Do not limit CSBs open up to non-profit community (utilize expertise) as grant process.	4	4	
RECOMMENDATION #21: Develop a training curriculum for first responders.			

JLARC STUDY RECOMMENDATIONS	Blue	Green	Red
A. Utilize and require training for first responders. (Training already exists.)	4		
B. Training curriculum <u>to include families of special need input</u> . Training should be mandated for all first responders both paid and volunteer.	8	6	
C. Include additional input from PSW as backdrop for recommendations.			
D. Adopt recommendation 1-4 from the Public Safety Workgroup requiring ongoing training.	1		
ADDITIONAL RECOMMENDATIONS			
- Provide long term Medicaid for everyone upon diagnosis.	15	7	
- Provide Assistive Tech training for educators and parents of all ages.	5	3	
- Go to private consulting (to evaluate, cost out & fix) for ideas on report recommendations.		1	
- Independent consulting organizations from outside to evaluate best practices and match recommendations.	5		
- Increase access to intensive direct home and community based early intervention services if not eligible for Medicaid or private insurance services through public funding as funded by state.	7		
- Definition of Autism: Neurobiological disorder diagnosed by a medical doctor	7	1	11
- Make a case management organization unable to provide other services (separation of case management and services)	11		
- Develop collaboration between public and private treatment and education.	11	4	
- Access - Affordability - Education - Health care - Employment - Public Safety			
- Today – What is the Problem? What needs to be done? Metrics – Scope of problem. What is the fix and cost (phase in option)?			
- Develop collaboration between public and private treatment facilities	6	2	

JLARC STUDY RECOMMENDATIONS	Blue	Green	Red
TRANSITION RECOMMENDATIONS			
- Weak in report	1		
- Need to promote self-advocacy	6		
- Need to discuss post secondary education – in all colleges	2		
- Need to discuss how we support individual choice			
- Need to discuss how we support families if individual stays at home.	3		
- Does data on number of youth employed 1 year out of school is bad = need to focus on High School IEP/transition practices			
- Ensure that “equal” advocacy for slot distribution (if current system used) among children and adults is used, not just individuals who have case management (put a child at a disadvantage)	5		
- Private practice doctors are already being run out of business due to Medicaid <u>not</u> paying industry standard, compensation to doctors treating children with ASD.	5		
- Chart on pg. 21, new ASD diagnosis doesn’t reflect increase in CDC new prevalence data. Need to specify numbers indicate a lack of adequate screening. Add another table showing the ASD prevalence over the <u>past 20 years</u> as recorded by CDC.	3		