



Behavioral Health Care Subcommittee

Needs of Individuals with Autism Spectrum Disorder Transitioning from Secondary Schools

SJR 330– Senator Northam

September 17, 2013

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Study Mandate

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

Agenda

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

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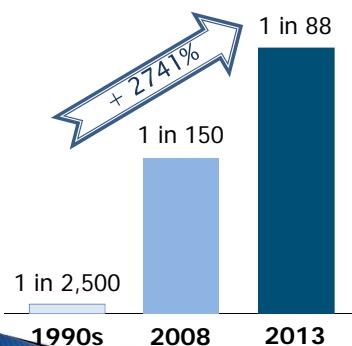
Background

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

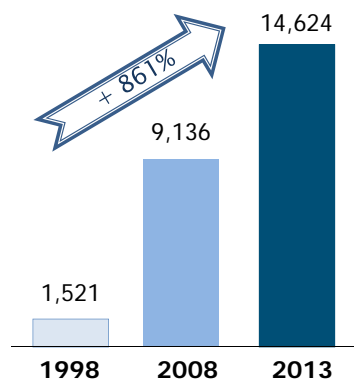
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Prevalence of Diagnosed ASDs Increased Dramatically in Past 15 Years

**National Estimated
Prevalence Rate of ASDs**
(Centers for Disease Control)



**Virginia Students With ASDs
in Special Education**



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Prevalence of ASD in VA

► Children with Autism in Virginia:

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

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Prevalence of ASD in VA

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

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Costs Associated with ASD

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

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

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

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Funding and Programs for Adults (22+) with ASD

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

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Primary Needs of Adults with ASD

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

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Adults with ASD Age out of Entitlement System

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

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Medicaid Waivers

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

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Medicaid Waivers

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

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DOJ Settlement and Waiver Reform

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

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TRANSITION PLANNING

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The Importance of Transition

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

Virginia ASD Transition Indicators

| | 2010 | 2011 | 2012 |
|---|------------|------------|------------|
| Advanced Diploma | 51 (.5%) | 54 (.5%) | 51 (.5%) |
| Standard Diploma | 99 (.9%) | 106 (1.0%) | 148 (1.4%) |
| Modified Diploma | 23 (.2%) | 22 (.2%) | 35 (.3%) |
| Special Diploma | 73 (.7%) | 121 (1.2%) | 97 (.9%) |
| In Business or Company | 29 (1.1%) | 21 (.8%) | 63 (1.6%) |
| Sheltered Employment | | | 11 (.3%) |
| Employed, not competitively | 39 | 50 | 56 |
| Other Employment | 53 | 59 | 68 |
| 2-4 Year College | 110 (4.3%) | 89 (3.6%) | 123 (4.8%) |
| Training Program | | 18 (.3%) | 14 (.2%) |
| Day Support | | 23 (.4%) | 12 (.2%) |
| No participation in postsecondary education of training program | | 69 (1.1%) | 70 (1.1%) |
| Unengaged | 33 (4.5%) | 45 (5.3%) | 41 (4.7%) |

Individuals with Disabilities Education Act (IDEA) Provisions

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

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Transition Planning

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

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Transition Team

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

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2009 JLARC Report Also Addressed Transition Services

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

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Virginia DOE Transition Guidelines

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

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Virginia DOE and Transition

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

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Coordination and Collaboration

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

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Coordination and Collaboration

- ▶ Even though DBHDS has become the lead agency, it still remains difficult for families to navigate the system.
 - Many families continue to report they too often do not understand waivers or their options for financial assistance, employment, and housing.
- ▶ Although DBHDS has given the responsibility for maintaining a website on ASD and transition services to Commonwealth Autism Service, there is no easily accessible link to this information on the DBHDS website.

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Case Management

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

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Case Management

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

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Higher Education/Employment

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Virginia DOE Diplomas

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

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Post-Secondary Education

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

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ASD and Employment

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

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ASD and Employment

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

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DARS Services

- ▶ DARS is the agency responsible for providing employment supports for individuals with ASD.
- ▶ DARS is seeing a steady increase in applications for services by people with ASDs.
 - In 2010, 1,029 people with ASDs were served, up from 737 in 2008.
 - In addition in 2010, 88% of those served were transition age youth.
 - These individuals often have higher support needs and thus require more extensive vocational rehabilitation services than other individuals with disabilities served by DARS.
- ▶ Since the JLARC report, DARS has been using its budget to improve vocational services for individuals in transition.

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DARS Order of Selection

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

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Long-Term Support Services

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

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Examples of DARS Programs and Services

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

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Other Employment Initiatives

- ▶ Project SEARCH
- ▶ DBHDS Employment First Initiatives:
 - Governor's Executive Order 55
 - Virginia must provide integrated day activities and significantly shift the number of individuals in day support programs to integrated day opportunities, including supported employment.
 - Strategize on ways to reach out to business communities to educate and increase awareness of employing persons with disabilities.
 - Revise Waiver Day Support regulations to increase flexibility and emphasis on employment as the priority focus.

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Housing

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Transition to Housing

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

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Current Housing Options

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

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Transition to Housing

- ▶ The current waiver system is based on diagnosis and acts as a barrier to persons with ASD in finding housing.
 - Only those individuals with an intellectual disability and on the ID Waiver are entitled to In-Home Residential Support in congregate group homes and congregate sponsored services.
 - The DD waiver does not cover housing costs.
 - An ID diagnosis is required to receive supported housing, which places the disability communities at odds with each other.
 - For example, a young adult with severe ASD and no intellectual disability may qualify for the DD waiver, which covers In-Home Residential Support in the client's own home, but not in a congregate or group home facility.

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Transition to Housing

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

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DBHDS Current Housing Efforts and the DOJ Settlement

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

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Policy Options

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Policy Options

Option 1: Take no action.

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

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

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

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Policy Options

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

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

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

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

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Public Comment

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

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

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