Autism Spectrum Disorders: Recent Reviews and Legislative Actions

"Autism spectrum disorders (ASDs) are a group of developmental disabilities defined by significant impairments in social interaction and communication and the presence of unusual behaviors and interests....The thinking and learning abilities of people with ASDs can vary – from gifted to severely challenged. ASD begins before the age of 3 and lasts throughout a person's life. It occurs in all racial, ethnic, and socioeconomic groups and is four times more likely to occur in boys than girls." The most recent estimate indicates an average of 1 in 110 children have an ASD in the United States. **Source:** *Autism Information Center*, Centers for Disease Control and Prevention Website.

2005 BHC Review	Behavioral Health Care (BHC) Subcommittee – Timeline BHC Subcommittee began review of issues related to services for children with an ASD. The Subcommittee identified the significant educational and support needs of children with ASDs
2006 General Assembly Session	HJR 96 and SJR 125 (companion resolutions) were introduced on behalf of JCHC and adopted unanimously by the General Assembly.
	The resolutions requested: (i) that the Department of Education continue to implement initiatives to strengthen teacher qualifications related to the needs of children with ASDs; and (ii) that the Department of Mental Health, Mental Retardation and Substance Abuse Services assist in expanding "training opportunities that include approaches specifically addressing the needs of children with autism spectrum disorders"
2006 BHC Review	BHC Subcommittee continued its review of ASD services and heard from representatives of the VCU Treatment Center for Children, the Department of Education, and the Virginia Autism Resource Center regarding the needs of individuals with an ASD. The issue of designating an agency to be the State "home" for ASD services was discussed. The absence of a State home meant that no one agency had responsibility for or the legislative mandate to develop policy, to plan and coordinate service delivery, to request funding, or to undertake strategic planning for the needs of an ever-increasing number of Virginians with an ASD.
2007 General Assembly Session	A budget amendment of \$288,500 was introduced on behalf of the JCHC to enable VCU to administer training and technical assistance activities related to working with individuals with ASD. Funding was not included in the approved State budget.
2007 BHC Review	BHC Subcommittee voted to convene a workgroup to develop a consensus regarding which State agency should be established or designated as the lead agency for ASD services. Four work-group meetings were held involving a diverse membership representing the interests of individuals with ASDs, intellectual disabilities, and other developmental disabilities. Although no clear consensus was reached regarding the entity which should serve as the lead agency, agreement was reached regarding key issues to be considered in establishing a lead agency.
2008 General Assembly Session	JCHC introduced a budget amendment requesting that the Secretary of Health and Human Resources develop and report on an Implementation Plan to determine the State agency that should be responsible for serving individuals with ASDs (and determine whether the agency should serve individuals with other developmental disabilities).
	Although the suggested language was not included in the approved budget, a letter was sent by the JCHC Chairman asking the Secretary of Health and Human Resources to develop and report on an Implementation Plan.
2008	JCHC Report issued: <i>Lead Agency to Serve Individuals with Autism Spectrum Disorder</i> , RD 147 (2008).

Review by the Secretary of Health and Human Resources

Deputy Secretary Dix reported to JCHC in October 2008 regarding the Secretary's efforts to develop an implementation plan.

"The Secretary of Health and Human Resources (SHHR) convened a second advisory committee in...2008, inviting those organizations and representatives that participated in the 2007 committee [that have been convened by JCHC staff]. The SHHR also included self-advocates that represented different types of developmental disabilities (Autism, intellectual disabilities, cerebral palsy, etc.) and their families....

The Secretary requested that the reconstituted group focus on developing a basic implementation plan for placing the "home" for ASD services at the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS). She requested that the stakeholder advisory panel pinpoint a plan for establishing a home for ASD, and recommend ways to move towards an umbrella system that would make DMHMRSAS the home for coordination and oversight of services for all developmental disabilities....The stakeholder group identified a practice area at DMHMRSAS as a critical step in moving toward a more comprehensive DD system. This DMHMRSAS office would include at least two people, hired from a pool of qualified persons who are currently not employed within the Department, who have expertise in ASD and developmental disabilities....

Summary

The merger of services to all individuals with developmental disabilities, including ASD, under one state agency umbrella will facilitate a more coordinated and integrated delivery system in Virginia. The recommendation to house ASD and developmental disabilities within DMHMRSAS and the corresponding action plan represents the best thinking of those stakeholders who partnered in this process to outline the steps necessary to envision the future and act on it."

Source: *Report on "Home" for Autism Spectrum Disorders and Developmental Disabilities* presented by Heidi Dix, Deputy Secretary, Office of the Secretary for Health and Human Resources to JCHC on October 23, 2008.

2009SB 1117 (Ticer) and HB 2300 (Caputo) were enacted changing the name of DMHMRSAS to the
Department of Behavioral Health and Developmental Services (DBHDS).Session

July 2009 DBHDS assumed responsibility for developing an action plan for serving the needs of individuals with an ASD or other developmental disability.

Reviews by Joint Legislative Audit and Review Commission (JLARC)

In 2008, JLARC reviewed the merits of mandated health insurance coverage for habilitative services (services typically used in the diagnosis and treatment of ASD) for children as required in HB 83 (R.G. Marshall). The JLARC review indicated: "There appears to be a need for health insurance coverage of ASD-related services, and coverage of these services appears consistent with the role of health insurance as evidenced by several insurers providing this coverage, autism mandates in other states, and coverage of these services by the U.S. Military health plan. It may be desirable to require that treatments covered by HB 83 be provided by certified or licensed providers and that only evidence-based treatments are covered to ensure that children are receiving safe and effective

treatments. Also, capping the annual coverage amounts, as other states have done, would help reduce the potential impact on premiums of the mandate. It may be premature to consider adopting an insurance mandate for ASD-related services prior to the results of a separate JLARC study [as required by HJR 105 of 2008] that is assessing the availability and delivery of services to individuals with ASDs in Virginia, including the coordination of these services."

Source: JLARC's Evaluation of House Bill 83: Mandated Coverage of Autism Spectrum Disorders, RD 265 (2008), p. ii.

The Special Advisory Commission on Health Insurance Mandates considered the JLARC recommendation and voted in support of the mandate.

2009 HB 1588 (R. G. Marshall) to mandate health insurance coverage for ASD, was left in the House General Assembly Session

In 2009, JLARC reported on its two-year study of autism services, as requested in HJR 105 (Valentine) of the 2008 General Assembly Session. The JLARC report, *Assessment of Services for Virginians with Autism Spectrum Disorders*, HD 8 (2009), included the following key findings:

- Despite existing programs, needs of some Virginians with ASDs are not met
 - o Lack of coordination undermines efficiency and effectiveness of services
 - o Many children appear to be diagnosed later than is possible
 - Early intervention programs do not provide intensity shown to maximize outcomes and reduce costs
 - Schools cannot consistently meet all the needs of students with ASDs or facilitate their independence
 - Limited supports exist for adults, and employment supports are hindered by capacity constraints
- Numerous options exist for Virginia to improve delivery of services to individuals with ASDs by
 - o Enhancing efficiency through greater coordination and collaboration
 - Bolstering effectiveness of existing programs through application of best practices and outcome measures
 - o Alleviating service gaps, especially in early intervention

The JLARC report included 21 recommendations including a recommendation that State agencies responsible for Medicaid, education, health, rehabilitation, criminal justice, and judicial services consider the options and make recommendations to DBHDS in early 2010. DBHDS was asked to consider those recommendations and the JLARC findings in creating "a detailed action plan to 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."

Source: JLARC report Assessment of Services for Virginians with Autism Spectrum Disorders, HD 8 (2009), p. 178.

Actions by Department of Behavioral Health and Developmental Services

In July 2009, DBHDS assumed responsibility for developing the action plan (recommended in the JLARC report) and added two positions including an ASD specialist and a developmental disabilities specialist. As noted previously, the action plan will be presented in November.