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Staff Update: JLARC Report on Services for Virginians with Autism Spectrum Disorders

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CDC Background on Autism Spectrum Disorders (ASDs)

- ❖ **“What is autism?”**
Autism spectrum disorders are a group of developmental disabilities defined by significant impairments in social interaction and communication. . . . 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.
- ❖ **What causes autism?**
We have learned a lot about the symptoms of ASDs...but we still don’t know a lot about the causes of ASDs. Scientists think that both genes and the environment play a role, and there might be many causes that lead to ASDs.
 - Studies have shown that among identical twins, if one child has autism, then the other will be affected about 75% of the time. In non-identical twins, . . . the other has it about 3% of the time. Also, parents who have a child with an ASD have a 2%–8% chance of having a second child who is also affected.
- ❖ **What is the prevalence of autism?**
CDC’s Autism and Developmental Disabilities Monitoring Network released data in 2007 that found about 1 in 150 8-year-old children in multiple areas of the United States had an ASD.
 - . . . using the prevalence data stated above...estimate that up to 560,000 individuals between the ages of 0 to 21 [in the US] have an ASD.”

Source: *Autism Information Center*, Centers for Disease Control and Prevention website.

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JCHC's Prior Consideration of ASD Policy and Services

- ❖ JCHC, through the Behavioral Health Care Subcommittee began its review of services for Virginians with ASDs four years ago:
 - In 2005, public school representatives spoke regarding the importance of teacher training.
 - In 2006, representatives of the Virginia Autism Resource Center, the Virginia Treatment Center for Children, and the Dept. of Education (DOE) reported on the increasing number of children diagnosed with and receiving special education services related to ASDs and that there was no statewide system of service provision or “home agency” for ASDs in Virginia.
 - In 2007, JCHC staff convened a work group in an effort to reach a consensus regarding establishing a lead agency for ASD. While consensus on a specific agency was not reached, the majority of participants endorsed the option to ask the HHR Secretary to develop and report on an implementation plan for establishing a lead agency; including whether the agency would serve individuals with ASD only or other developmental disabilities also.
 - In 2008, Dep. Secretary Dix reported on the details of the plan for DMHMRSAS (now Dept. of Behavioral Health & Developmental Services – DBHDS) becoming the lead agency for developmental disabilities services and policies.



HJR 105 of 2008 (Valentine) Directed JLARC to Study Autism Services in the Commonwealth

- ❖ The JLARC study noted that certain intensive early intervention treatments can result in significant improvement for individuals with ASDs and result in cost savings.
 - Research indicates that young children “who participate in intensive early intervention programs based on ABA [applied behavioral analysis] principles experience improvements, with almost half achieving normal levels of functioning and another 40 percent realizing moderate gains....[reducing] public costs by decreasing the need for special education and other forms of public assistance, with savings likely to accrue over the lifetime of individuals with ASDs.”

Source: JLARC Final Report, *Assessment of Services for Virginians with Autism Spectrum Disorders*, 2009, p. ii.



Selected Key Findings from JLARC Report

- ❖ While the Commonwealth operates a number of programs which serve individuals with ASDs (through VDH, DMAS, DBHDS, DOE, DRS), there is no publicly-funded comprehensive system of care.
- ❖ There is no comprehensive source of information “to educate Virginians about ASDs and available services, and case managers are not consistently available to facilitate access to care.”
- ❖ Although early identification of ASD is important and possible (particularly between age two and three years), in Virginia “children are often diagnosed later and may therefore experience delays in receiving early intervention services.”
- ❖ “Early intervention programs serving young children with ASDs do not always include components that have been shown to yield positive outcomes, such as providing intensive interventions and using research-based practices.”

Source: JLARC Final Report, *Assessment of Services for Virginians with Autism Spectrum Disorders*, 2009, pp. i.



Selected Key Findings from JLARC Report

- ❖ “Many schools lack the guidance, training, and tools needed to uniformly meet the multifaceted needs of students with ASDs or adequately prepare them for future independent living.”
- ❖ Many “adults with ASDs require ongoing services and supports that are not widely available in Virginia, and may have to rely instead on public assistance programs.”
- ❖ There are limited training opportunities to assist public safety personnel in responding to “situations involving persons with ASDs...and most are offered only to law enforcement agencies.”

Source: JLARC Final Report, *Assessment of Services for Virginians with Autism Spectrum Disorders*, 2009, p. i.



Recommendation Involving JCHC from JLARC Report

- ❖ One recommendation requested that the **Dept. of Medical Assistance Services (DMAS)** “present a detailed plan outlining its proposed outreach efforts” to **JCHC** by November 30, 2009.
 - DMAS “should develop and implement a plan for educating Virginians with...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 [such as the Early and Periodic Screening, Diagnosis, and Treatment program] through which needed services can be obtained.

Source: JLARC Final Report, *Assessment of Services for Virginians with Autism Spectrum Disorders*, 2009, pp. 98.



Funding Options Presented in JLARC Report

- ❖ In addition to the use of State funding, JLARC indicated that “the role of other public and private sources could also be explored to share the cost...in a fair and appropriate manner. In particular, the State could
 - expand Medicaid programs and receive federal matching funds for 50 percent of expenditures;
 - launch pilot programs using short term funding from the federal American Recovery and Reinvestment Act and subsequently expand initiatives that successfully address the needs...;
 - reinvest savings derived from efforts to either increase the efficiency of existing programs or alleviate service gaps, especially in the early intervention system;
 - re-examine the extent to which localities should support program expenditures or require local matching funds for new services;
 - enact legislation requiring health insurers to offer comprehensive coverage for ASD-related services; and
 - require the contribution of personal resources based on the individuals’ ability to pay.”

Source: JLARC Final Report, *Assessment of Services for Virginians with Autism Spectrum Disorders*, 2009, p. x.



Options to Improve Service Coordination, from JLARC Report

- ❖ Design a reliable source of information to educate Virginians about ASDs and available services
 - Guidebook
 - Website
 - Staffed clearinghouse.
 - **Recommendation:** DBHDS to select and design most appropriate mechanism for sharing information.
- ❖ Improve case management
 - Caregivers trained on effective case management practices
 - Expanded role of existing case managers
 - Regional case management for all Virginians with ASDs.
 - **Recommendation:** DBHDS to evaluate options and identify which to pursue by March 2010.
- **Recommendation:** DBHDS to collaborate with stakeholders to create detailed action plan for addressing issues contained in JLARC study and report findings to HHR Secretary, Chairmen of HAC and SFC by November 2010.

Source: JLARC Final Report, *Assessment of Services for Virginians with Autism Spectrum Disorders*, 2009, pp. 43-51, 178.



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Options to Facilitate Earlier Identification and Diagnosis of ASDs, from JLARC Report

- ❖ Raise public awareness about ASDs
 - Information packets
 - Media campaign.
- ❖ Increase consistent and standardized ASD screening through training
 - Physicians
 - Non-medical personnel (Part C, teachers, daycare, etc.).
- ❖ Expedite access to diagnosis by increasing capacity
 - Pediatricians trained to diagnose
 - Regional offices.
- ❖ Improve referral process
 - Better information to parents and physicians
 - Multidisciplinary, comprehensive plans of care.
- **Recommendation:** DBHDS to evaluate options and identify which to pursue by March 2010.

Source: JLARC Final Report, *Assessment of Services for Virginians with Autism Spectrum Disorders*, 2009, pp. 61-71.



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Options to Improve Early Intervention Programs, from JLARC Report

- ❖ Increase intensity of services
 - More hours of direct services through Part C program
 - Lower child-to-staff ratios; increase access to full-day, year round preschools through Part B program.
- ❖ Train all providers on ASD-specific interventions.
- ❖ Enhance reliance on outcome measurements and data-driven planning.
- ❖ Improve access to Medicaid programs
 - ASD provider standards and tiered rates based on expertise
 - ASD therapies added to existing waivers
 - New ASD waiver.
 - **Recommendation: DMAS** to educate families about availability of all programs and services available to individuals with ASDs, especially with regards to eligibility for the EDCD waiver and EPSDT.
- ❖ Develop new early intervention programs
 - Regional offices
 - Tuition grant program.
 - **Recommendation: DBHDS, DOE , and DMAS** to evaluate options and identify which to pursue by March 2010; **DOE and DMAS** to report to **DBHDS**.

Source: JLARC Final Report, *Assessment of Services for Virginians with Autism Spectrum Disorders*, 2009, pp. 88-104.



Options to Improve ASD School Services, from JLARC Report

- ❖ Develop guidance on research-based practices.
- ❖ Identify and prioritize training needs.
- ❖ Increase qualifications of new and existing teachers
 - Requiring or encouraging ASD coursework.
- ❖ Improve access to ASD experts at local and State levels.
- ❖ Enhance schools' ability to develop student goals and track progress.
- ❖ Create transition specialist positions.
- ❖ Expand vocational and life skills training.
- **Recommendation: DOE, DMAS, and DBHDS** to evaluate options and identify which to pursue by March 2010; DOE and DMAS to report to DBHDS.
- **Recommendation: DOE** should:
 - Collaborate with the Office of the Attorney General to develop guidelines for interpreting "free and appropriate education" and
 - Develop model individualized education programs (IEPs) and transition guidelines for students with ASDs.

Source: JLARC Final Report, *Assessment of Services for Virginians with Autism Spectrum Disorders*, 2009, pp. 126-141.



Options to Foster Greater Independence Among Adults, from JLARC Report

- ❖ Improve employment services and supports
 - Train staff from Dept. of Rehabilitative Services (DRS) to work with clients with ASDs
 - Provide social and communication skills training
 - Expand Long-Term Employment Support Services program
 - Reduce or eliminate waiting lists for DRS services.
- ❖ Expand Medicaid services
 - Add congregate care to DD waiver
 - Review provider rates.
- ❖ Develop pilot program for comprehensive adult services.
- **Recommendation: DRS, DMAS, and DBHDS** to evaluate options and identify which to pursue by March 2010; **DRS and DMAS** to report to **DBHDS**.
- **Recommendation: Olmstead Implementation Team** to focus on development of services for adults with ASDs.

Source: JLARC Final Report, *Assessment of Services for Virginians with Autism Spectrum Disorders*, 2009, pp. 151-159.



Options to Enhance Public Safety Personnel Awareness of ASDs, from JLARC Report

- ❖ Use Virginia's Alzheimer awareness training as roadmap.
- ❖ Tools for delivering training
 - Range from simple carry-card to 2-hour workshop.
- ❖ Personnel to receive training
 - Law enforcement, emergency medical services, fire and rescue, and judicial personnel specifically mentioned.
- ❖ Mechanism to implement training
 - Facilitate access vs. mandate.
- **Recommendation: Dept. of Criminal Justice Services, VA Dept. of Health, and the Supreme Court of Virginia** to evaluate options and identify which to pursue by March 2010 and report to **DBHDS**.

Source: JLARC Final Report, *Assessment of Services for Virginians with Autism Spectrum Disorders*, 2009, pp. 167-173.



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