

Report on the Recommendations of the Virginia Autism Advisory Council 2014

Members

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The Honorable Thomas A. Greason, Vice Chair
The Honorable Stephen H. Martin
The Honorable Kenneth R. Plum
The Honorable Timothy D. Hugo
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Citizen Members:

Ms. Jennifer Lassiter
Mr. Krishna P. Madiraju

Staff:

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<http://dls.virginia.gov/commissions/aac.htm>

BACKGROUND

The Virginia Autism Advisory Council is the legislative body charged with promoting coordination of services and resources among agencies involved in the delivery of services to Virginians with autism spectrum disorders (ASDs) and increasing public awareness of such services and resources. The following is a summary of the Council's progress updates and recommendations.

MEETINGS

Tuesday, June 17, 2014

Overview of the Autism Advisory Council

Sarah Stanton and Ryan Brimmer, staff attorneys with the Division of Legislative Services, provided a brief overview of the Council's scope, purpose, membership, and prior activities.

PRESENTATION: Department of Behavioral Health and Developmental Services

Mr. Connie Cochran, Assistant Commissioner for Developmental Services at the Department of Behavioral Health and Developmental Services (DBHDS), gave a presentation on current programs and efforts designed to assist individuals with autism. Mr. Cochran explained that DBHDS provides many services through contracts with community services boards. He spoke about the Commonwealth's intellectual and developmental disability waivers, the extensive waiting list for waivers, and new waiver slots created through the Commonwealth's August 23, 2012, settlement agreement with the U.S. Department of Justice. Mr. Cochran also outlined a recently-approved employment program waiver, which better enables individuals with autism to move directly from school to employment through a collaborative effort by DBHDS, the Department for Aging and Rehabilitative Services, and the Department of Education (DOE). Finally, Mr. Cochran explained that other efforts are being made through the Early Childhood Intervention Part C Program and crisis services programs for children, adults, and families.

PRESENTATION: Department of Education

Mr. John Eisenberg, Assistant Superintendent for Special Education and Student Services at the DOE, spoke about special education programs in use by the DOE that assist children with autism, including self-paced online programs that have garnered significant participation. Mr. Eisenberg stated that the DOE has been working closely with select school divisions and that significant statistical improvements in performance have been measured in those divisions. Mr. Eisenberg further stated that the number of children diagnosed with autism has grown 245 percent since 2006, totaling approximately 15,859 students in the Commonwealth's school system. Mr. Eisenberg noted that the primary diagnostic tool used to identify autism in children is the Autism Diagnostic Observation Schedule. Finally, Mr. Eisenberg gave positive remarks on Project Search, an internship-type program for high school students with autism that is making it easier for these students to secure employment upon graduation.

PRESENTATION: Autism, Dyslexia, and the Issue of Misdiagnosis

Ms. Kim Stump spoke about her son's experiences with dyslexia and their family's difficulties in diagnosing her son's condition. Ms. Stump explained that many teachers are unaware of dyslexia and its symptoms, which in her view contributed to delays in diagnosing her son. Ms. Stump further stated that children with dyslexia, like her son, are often misdiagnosed with, among other conditions, autism, Asperger syndrome, and attention deficit disorder. Ms. Stump opined that the Commonwealth's teachers need more access to and familiarity with information about dyslexia so that other children and families do not have to suffer misdiagnoses and delayed diagnoses like her family. Ms. Stump recommended that training on dyslexia be included in teachers' undergraduate programs. She explained that her son was taking a long time to complete his homework and was otherwise struggling in school and asserted that because children with dyslexia learn in certain ways, it is important that they are diagnosed early in order to provide them the assistance they need. Ms. Stump opined that such assistance should be provided in public schools, noting that such services are extremely expensive in a private setting. Ms. Stump also voiced concern that more assistance is being provided to dyslexic children in some school divisions than in others. Ms. Stump noted that dyslexia is much more than simply seeing things backwards; affecting one in five people, dyslexia affects various parts and functions of the brain. She explained that individuals with dyslexia are very intelligent in certain areas and maintained that over 50 percent of NASA employees are dyslexic.

Discussion of 2014 Work Plan

The meeting continued with discussion of the 2014 work plan. The Council plans to formulate potential strategies for lowering the current waiver waiting lists and evaluate the adequacy of the Commonwealth's current employment support programs and efforts for students with autism. The Council further intends to assess the issue of uniform application of dyslexic and autism support across the Commonwealth. The Council plans to invite parents of children with autism and dyslexia from various regions in the Commonwealth to testify before the Council regarding their satisfaction and experiences with the services being provided in their area. The Council also plans to focus on the issue of proper diagnosis.

Monday, September 22, 2014

PRESENTATION: 2014 Assessment of the Disability Services System in Virginia

Ms. Heidi Lawyer, Executive Director, Virginia Board for People with Disabilities, provided an overview of the Disability Services System in Virginia and presented recommendations for improvements to the system adopted by the Virginia Board for People with Disabilities. The Board is required by the *Code of Virginia* to "submit every three years to the Governor, through the Secretary of Health and Human Resources an assessment of the needs of persons with disabilities in the Commonwealth, the success in the preceding three years of the state agencies in meeting those needs, programmatic and fiscal recommendations for improving the delivery of services to persons with disabilities, and an assessment of the triennial economic cost and benefit to the Commonwealth of the services and rights afforded persons with

disabilities." The assessment is intended to assist in public policy decision-making and to provide a resource guide and reference tool for decision makers. The assessment reviews services and supports that are funded, operated, administered or licensed by the Commonwealth for Virginians with developmental or related disabilities and addresses services across the lifespan, including: early intervention, education, employment, community supports, health care, Medicaid services, housing, transportation, and institutional care. In presenting recommendations to the Council, Ms. Lawyer focused on those related to early intervention, education, employment, and Medicaid. A copy of her presentation, including the recommendations presented, can be found on the Autism Advisory Council's website at: http://services.dlas.virginia.gov/User_db/frmView.aspx?ViewId=4119&s=26.

PRESENTATION: Employment Services for Individuals with Autism

Dr. Joe Ashley, Assistant Commissioner, Department for Aging and Rehabilitative Services, presented information employment-related services and programs for individuals with autism provided by the Department for Aging and Rehabilitative Services. Dr. Ashley provided information on DARS autism service trends; current autism projects including Project SEARCH, DARS Autism Subject Matter Experts, Central Office technical assistance, coordinated and comprehensive service planning, integration of Positive Behavioral Supports and hand-held technology interventions, and development of infrastructure within DARS and across adult services providers; and issues and barriers to current services and future plans. A copy of Dr. Ashley's presentation can be found on the Autism Advisory Council's website at: http://services.dlas.virginia.gov/User_db/frmView.aspx?ViewId=4117&s=26

PRESENTATION: Virginia Developmental Disability Services and Supports

Ms. Cindy Gwinn, Community Resource Manager Autism Specialist, Department of Behavioral Health and Developmental Services, provided a brief overview of the Commonwealth's developmental disability services and supports. The Commonwealth's program of services and supports for individuals with disabilities include services provided by the Secretaries of Health and Human Services, Education and Public Safety through the Department of Behavioral Health and Developmental Services, the Department of Education, the Department for Aging and Rehabilitative Services, the Department of Medical Assistance Services and the Department of Criminal Justice Services. Non-profit state-funded agencies, advocacy groups and other stakeholders also work with state agencies to meet service needs. A copy of Ms. Gwinn's presentation can be found on the Autism Advisory Council's website at: http://services.dlas.virginia.gov/User_db/frmView.aspx?ViewId=4116&s=26.

STAKEHOLDER COMMENT

Following presentations, the Council received public comment.

- Mr. Brett Willis, a Medicaid autism services coordinator for individuals with autism and parent of a child with autism, spoke about the challenges faced by parents attempting to navigate the autism services and Medicaid waiver systems, long waiting lists for services, limited access to autism services particularly for

individuals who don't qualify for Medicaid, and difficulties associated with attempting to enroll in Medicaid waiver services.

- Ms. Bradford Hulcher, program director with the Autism Society and parent of a child with autism, described the work of the Autism Society and identified several challenges faced by individuals with autism and parents of children with autism including difficulties in having children formally diagnosed; long waits for formal diagnosis resulting in delays in accessing services; trouble accessing intensive intervention services through the Early Intervention program; insufficient behavioral supports in schools; insufficient employment training services for students with autism resulting in students exiting public schools without the necessary skills for meaningful, integrated employment; insufficient support for students transitioning from school to higher education and employment and their families; lack of a single point of entry into the autism services system; long waiver waiting lists and difficulties in accessing the waiver system; a lack of systematic training for emergency responders and individuals involved in the courts system; and a lack of community crisis supports for children with autism and their parents.
- Ms. Karen Isik, parent of a child with autism, described the challenges she faced in navigating the autism services system on behalf of her child, including long waiting lists for services, particularly the initial assessment; waiting lists for waivers; and challenges in getting her child included on waiver waiting lists. She recommended that the Council look into ways to streamline the process, improve communication among services providers, and educate physicians regarding their role in the autism identification and diagnosis process.

Wednesday, November 12, 2014

PRESENTATION: Navigating the Service System: Waivers and Autism

Ms. Cindy Gwinn, Community Resource Manager Autism Specialist, Department of Behavioral Health and Developmental Services, provided an overview of the Medicaid Waiver system generally and services for individuals with autism specifically. She provided information on the prevalence of autism, the types of waivers and services available to individuals with autism, and the process for accessing waiver services. She also noted that the Commonwealth is in the process of redesigning its system of waivers and waiver services. A copy of Ms. Gwinn's presentation can be found on the Autism Advisory Council's website at http://services.dlas.virginia.gov/User_db/frmView.aspx?ViewId=4176&s=26.

Following Ms. Gwinn's presentation, the Council discussed challenges faced by individuals seeking waiver services. Specifically, members noted extensive waiting lists for waiver services and challenges faced by parents in navigating the waiver enrollment process.

DISCUSSION: Preliminary Recommendations for 2015

Members of the Autism Advisory Council discussed preliminary recommendations received at previous meetings, including recommendations adopted by the Virginia Board for People with Disabilities and presented to the Council for their consideration. A document setting out preliminary recommendations can be found on the Autism Advisory Council's website at http://services.dlas.virginia.gov/User_db/frmView.aspx?ViewId=4173&s=26.

Monday, December 8, 2014

PRESENTATION: Connor's Law

Ms. Sharon Cummings and Mr. Connor Cummings presented information on proposed legislation, known as Connor's Law, which would allow a court to order child support for any child over the age of 18 who is severely and permanently mentally or physically disabled if such disability existed prior to the child reaching the age of 18 or the age of 19 if the child was a full-time high school student, not self-supporting, and was living in the home of the parent seeking child support. Currently, the law allows a court to order the continuation of child support ordered before the child reached the age of 18 after the child reaches the age of 18 if the child severely and permanently mentally or physically disabled, unable to live independently and support himself, and resides in the home of the parent seeking or receiving child support, but does not allow the court to enter an order establishing child support if the child has reached the age 18 without child support previously being established. Ms. Cummings noted that Senator Favola will be introducing legislation to make this change during the 2015 Session. The Council voted to support legislation establishing Connor's Law during the 2015 Session.

PRESENTATION: Autism Spectrum Disorder: Current Research

Ms. Cindy Gwinn, Community Resource Manager Autism Specialist, Department of Behavioral Health and Developmental Services, provided information about current research into the causes and treatment of autism. A copy of her presentation can be found on the Autism Advisory Council's website at: http://services.dlas.virginia.gov/User_db/frmView.aspx?ViewId=4245&s=26.

DISCUSSION & VOTE: Recommendations for 2015

Following presentations, the Council discussed final recommendations for 2014. The Council adopted the following recommendations:

- The General Assembly should provide sufficient long-term funding to eliminate waiting lists for vocational rehabilitation and eliminate the Order of Selection.
- The General Assembly should reduce waiting lists for ID/DD waivers by providing additional funding for waiver slots.
- The General Assembly should adopt legislation requiring the Board of Medicine to work with other stakeholders to develop information about the role of physicians in

identifying and diagnosing autism and helping individuals with autism access waiver services, and facilitate its distribution.

The Council also voted to support 12 recommendations presented to the Council at the September meeting by the Virginia Board for People with Disabilities. The Council voted not to support one recommendation of the Virginia Board for People with Disabilities, which called for delaying plans for the expansion of coordinated care to Medicaid enrollees with an intellectual or other disability who receive supports under the ID or DD waivers as long as needed to ensure thoughtful planning, research, and stakeholder input. Instead, the Council stated that it supports taking steps to thoughtfully implement the expansion of coordinated care in a manner that takes into account the needs of individuals receiving services and ensures the needs of individuals with ID/DD receiving services are met.

Additional information about recommendations considered and adopted by the Council can be found on the Autism Advisory Council's website at:

http://services.dlas.virginia.gov/User_db/frnView.aspx?ViewId=4252&s=26.