

Report on the Interim Activity of the Autism Advisory Council 2021

Members

Legislative Members:

The Honorable Joshua G. Cole, Chair
The Honorable Glenn R. Davis, Jr.
The Honorable Emmett W. Hanger, Jr.
The Honorable Kaye Kory
The Honorable J. Chapman Petersen
The Honorable Kenneth R. Plum

Citizen Members:

Ms. Dilshad D. Ali
Dr. Polly Panitz

Staff:

Julia Carlton, Attorney, Division of Legislative Services
Trevor Merrion, Staff Associate, Division of Legislative Services
Lindley Griffin, Senate Committee Operations

Website:

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

BACKGROUND

The Virginia Autism Advisory Council (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 disorder (ASD) and increasing public awareness of such services and resources. The following is a year-end summary of the Council's 2021 interim activity.

OVERVIEW

The Council met twice during the 2021 interim. The meeting summaries outlining the Council's work are attached. Additional information related to the Council may be found at <http://dls.virginia.gov/commissions/aac.htm>.

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Autism Advisory Council

August 18, 2021, at 2:00 p.m.

Pocahontas Building, Senate Committee Room A

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

The Autism Advisory Council (the Council) met in Richmond with Delegate Joshua G. Cole, chair, presiding.¹ The meeting began with the unanimous election of Delegate Cole as chair, followed by public comment and member discussion. Video of the meeting is available [online](#).

Public Comment

The members listened to public comment on a variety of issues impacting individuals with autism spectrum disorder (ASD) and their families in the Commonwealth, including the following:

Criminal Justice Reform and Training for Law-Enforcement Officers and Judges

Members of the public expressed concern that adults with ASD are not receiving pretrial diversion in the criminal justice system and inquired about the Council's plans for criminal justice reform for individuals with ASD in the 2022 Session of the General Assembly.

There was discussion of the need to train first responders and law-enforcement officers to ensure greater understanding of how sensory overload is experienced by individuals with ASD. While trainings exist, particularly a program developed by Niagara University, and public safety work groups with officers, magistrates, and other law-enforcement professionals have been convened in the past, such training has not been consistent across localities. It was also noted that although training programs exist, if they are not mandated, participation in these programs will remain low and their efficacy in diffusing situations and preventing dangerous behavior will be limited.

Additionally, during the member discussion, Delegate Kaye Kory summarized her work with The Arc of Northern Virginia to develop a training program for judges that would help ensure that the specific needs of individuals with ASD are addressed by the criminal justice system.

Department of Education's Extra Year of Eligibility and Other Issues

Several members of the public expressed an interest in knowing more about the Department's extra year of eligibility for students receiving special education services, which was provided for in the 2021 Budget Bill. It was noted that many families are not aware of this development and are therefore not likely to benefit from it.

Other education issues addressed included the variability across localities in staff training and standards for individualized education programs (often referred to as IEPs). It was noted that as students with ASD are transitioned into general education environments, which is the objective for most students, they often have less access to educators with ASD-specific expertise as a result.

¹ **Members Present:** Delegate Joshua G. Cole (chair), Senator Emmett W. Hanger, Jr., Delegate Glenn R. Davis, Delegate Kaye Kory (virtual), Delegate Kenneth R. Plum, Dilshad D. Ali, Dr. Polly Panitz (virtual)

Members Absent: Senator J. Chapman Petersen

Challenges Accessing Information

Several members of the public noted that a lack of awareness of services remains a limiting factor in acquiring care. Individuals receive support from various agencies, which complicates the ability to disseminate information quickly and clearly. One specific complaint was that the website of the Department of Behavioral Health and Developmental Services is not user-friendly. It was suggested that both Unite Virginia, a statewide technology platform initiated in 2020 to connect vulnerable Virginians to health and social services, and increased access to case management services may provide solutions to this problem in the future.

Medicaid Waiver Waitlist and Other Insurance Issues

Several members of the public noted the ongoing issue of long waitlists for individuals seeking Medicaid waivers in the Commonwealth. Due to the highly individualized nature of ASD, it was suggested that case management services should be covered by insurance to enhance care. Additionally, it was noted that insurance currently only covers applied behavior analysis (ABA) services, while there are situations where more developmental therapies are more indicated and supported by the medical literature.

Provider Shortage

Members of the public noted that the shortage of doctors, behavioral analysts, and caregivers who are qualified to either diagnose or treat ASD remains a major roadblock to providing adequate care to individuals with ASD in the Commonwealth. Without enough doctors trained to diagnose ASD, individuals cannot easily get the diagnosis they need to have insurance cover their support services. Without enough behavioral analysts to provide ABA services, many individuals with ASD ultimately transition from home-based to center-based care, limiting a parent's involvement in their care. Without enough caregivers to provide in-home support under Medicaid waivers, the efficacy of the waivers in improving an individual's care is limited. The provider shortage across the spectrum creates inequities in care between families from different socioeconomic backgrounds while the high rate of attrition among behavioral analysts and caregivers contributes to the inconsistency in the quality of services available. Members of the public also noted the lack of doctors and caregivers to treat adults with ASD, particularly those with comorbidities who need support services other than behavioral support. To address these issues and meet demand, several members of the public suggested better compensation was necessary to improve the recruitment and retention of providers. Other suggestions included training more pediatricians to be qualified to diagnose ASD, either by incorporating autism into the Virginia Mental Health Access Program curriculum or by implementing training programs that teach the Autism Diagnostic Observation Schedule.

Member Discussion

Members of the Council expressed an interest in hearing from a representative of the Department of Education at the Council's next meeting to learn more about (i) the extra year of eligibility for special education services and if it will apply to students intending to graduate in 2022, (ii) the plan for serving students with ASD if schools return to remote learning, and (iii) the steps the Department takes to determine how to best teach students with ASD in remote learning environments.

Additionally, members expressed an interest in hearing from a representative of the Department of Behavioral Health and Developmental Services to learn more about its website and in holding



remote Council meetings in the future where members would visit facilities in the Commonwealth caring for individuals with ASD to learn more about their work.

Members expressed their intention to use testimony from the public comment portion of the meeting as an outline for the Council's work plan in the 2021 interim.

With unanimous support from the members, the election of the Council's vice-chair was postponed to a subsequent Council meeting. The date and time of the next meeting were not set.

For more information, see the [*Commission's website*](#) or contact the Division of Legislative Services staff:

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Autism Advisory Council

December 6, 2021, at 1:00 p.m.

Electronic Meeting

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

The Autism Advisory Council (the Council) met electronically with Delegate Joshua Cole, chair, presiding.¹ The meeting began with introductions and opening remarks followed by presentations and discussion. Materials presented at the meeting are accessible through the *Commission's meetings webpage*.

Presentation: Services Provided by the Virginia Institute of Autism

Dr. Ethan S. Long, President and Chief Executive Officer, Virginia Institute of Autism

Dr. Long provided an overview of the Virginia Institute of Autism's various programs and services, including the James C. Hormel School in Charlottesville, which serves approximately 70 students ages six to 22 who have level II or level III autism spectrum disorder (ASD); an outpatient behavioral services program, which provides applied behavioral analysis (ABA), early intervention, and other services to approximately 70 families in the organization's service region; and the Center for Adolescent and Adult Autism Services, which provides a range of programs for enhancing the quality of life for individuals 18 years and older. Dr. Long noted that the organization was founded by families of kids with ASD and that it has emphasized from the beginning the use of evidence-based strategies and services that benefit both individuals and their families. Dr. Long also described the impact of the COVID-19 pandemic on the institute and explained that the organization's biggest challenge at the moment is recruiting and retaining staff. Regarding legislative priorities, Dr. Long identified rate setting, the transition of Children's Services Act services to the Virginia Department of Education (DOE), and public-private partnerships as areas that would benefit from further examination. The presentation was followed by member questions and discussion, exploring issues related to the availability of adult transition services, how the Virginia Institute of Autism is funded, and the importance of developing capacity in ways that allow programs to remain flexible and build on their successes.

Presentation: Services Provided by the Grafton Integrated Health Network

Scott Zeiter, Chief Strategy Officer, Grafton Integrated Health Network

Mr. Zeiter provided a timeline of the Grafton Integrated Health Network's development as an organization, highlighting state partnerships that enabled the organization to grow into the vast network of programs and services that it constitutes today. Founded in 1958, Grafton has locations in Berryville, Front Royal, Richmond, Strasburg, and Winchester, as well as Charles Town, West Virginia, and is the largest children's residential provider in the Commonwealth. The organization specializes in serving children with severe ASD and comorbidities and has worked closely with agencies of the Commonwealth to develop group home models that keep children in the community and reduce the need for training centers. Mr. Zeiter noted that Grafton

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Members Absent: Dr. Polly Panitz

has continually worked to hone best practices for the care of children with severe ASD and that staff members have been successful in both eliminating the use of seclusion and reducing the use of restraint by 99 percent. As an organization that primarily provides residential services, Mr. Zeiter underscored the tremendous impact the COVID-19 pandemic has had on Grafton, noting increased costs and challenges with staff recruitment and retention as major impediments to its operations. Regarding legislative priorities, Mr. Zeiter identified provider reimbursement for psychiatric residential treatment facilities and rate setting as areas to be examined further.

Presentation: Services Provided by the Virginia Department of Education

Dr. Samantha Hollins, Assistant Superintendent of Special Education and Student Services, Virginia Department of Education

Dr. Hollins described the role of the Department of Special Education and Student Services in providing instructional leadership to school divisions, teachers, and other entities and summarized recent developments in programs and policies affecting students with ASD. She reviewed recommendations from the Joint Legislative Audit and Review Commission (JLARC) in its 2020 study, *K-12 Special Education in Virginia*,² particularly in the areas of eligibility, individualized education plans (IEPs), transitions services, teacher training, and program monitoring and compliance, and how DOE had addressed each recommendation thus far. Dr. Hollins noted that special education currently represents DOE's most critical hiring shortage and that the codification of JLARC's recommendations will allow for greater resources to be committed to these endeavors. Dr. Hollins also reviewed ASD initiatives specific to the Commonwealth, including DOE's applied studies cohort study, the Self, Health, and Relationship Education (SHaRE) social emotional learning curriculum, the Virginia Public School Behavior Analyst Network (VAPSBAN), and the Virginia Commonwealth University Autism Center for Excellence (VCU-ACE). She emphasized that DOE's goal is to place students with ASD in the least restrictive environment possible and that novel approaches to behavioral intervention have shown promise toward this end. Member questions and discussion centered on the availability of services throughout the Commonwealth and the importance of involving parents in the development and implementation of IEPs.

Member Discussion

Following the presentations, members engaged in a general discussion of topics raised. There was an inquiry into the extra year of eligibility for special education services that DOE established in response to the COVID-19 pandemic, and Dr. Hollins provided a brief overview of how that policy revision had been utilized thus far. The issue of staff recruitment and retention addressed by the three presenters was echoed during the member discussion, who noted that the caregiver shortage compounds the Medicaid waiver waitlist issue, making it difficult for families to receive help in a timely manner. There was discussion of the need to increase rates for caregivers, and Mr. Zeiter explained how the COVID-19 pandemic had exposed the shortcomings of many public-private business models, as organizations are limited in their ability to respond to instabilities in the market by passing increased costs along to consumers.

The meeting adjourned at 2:40 p.m.

² The majority of these recommendations were codified by HB 2299/SB 1288 in the 2021 Special Session I of the General Assembly.



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