

REPORT ON THE INTERIM ACTIVITY OF THE AUTISM ADVISORY COUNCIL 2024

Members

Legislative Members:

Senator Stella G. Pekarsky, *Chair*
Senator Tara A. Durant
Delegate Laura Jane Cohen

Delegate Patrick A. Hope, *Vice-Chair*
Delegate Kathy KL Tran
Delegate Phillip A. Scott

Ex Officio Members:

Nelson Smith
Commissioner, DBHDS
Karen Shelton
Commissioner of Health
Lisa Coons
Superintendent of Public Instruction
Teri Morgan
Executive Director, Virginia Board for People with Disabilities

Kathryn Hayfield
Commissioner, DARS
James H. Williams
Acting Commissioner, DSS
Cheryl Roberts
Director, DMAS

Citizen Members:

Conner Cummings
Parthenia Dinora
Jaime Hanks
Giovanni Knight
Mia Louria
Tonya Milling

Beth Davis
Ann Flippin
Whitney King
Ethan Long
Brian McCann
Rose Nevill

Staff:

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BACKGROUND

The Autism Advisory Council (Council) was established in 2024 in Chapter 50.1 (§ 30-329.1 et seq.) of Title 30 of the Code of Virginia for the purpose of promoting the coordination of services and resources among agencies involved in the delivery of services to Virginians with autism spectrum disorders and to increase public awareness of such services and resources. In fulfilling such purpose, the Council has the following powers and duties:

1. Facilitating the coordination of services and resources among agencies involved in the delivery of services to Virginians with autism spectrum disorders;
2. Monitoring the implementation of action plans developed by agencies in response to the report of the Joint Legislative Audit and Review Commission entitled "Assessment of Services for Virginians with Autism Spectrum Disorders," House Document No. 8 (2009);
3. Recommending policies, legislation, and funding needed to implement the action plans developed in response to the report of the Joint Legislative Audit and Review Commission entitled "Assessment of Services for Virginians with Autism Spectrum Disorders," House Document No. 8 (2009) and address other emerging issues; and
4. Determining services, resources, and policies that may further address the needs of individuals with autism spectrum disorders.

OVERVIEW

The Council held one meeting during the 2024 interim prior to the December 1, 2024 reporting deadline established pursuant to subsection B of § 30-329.2. The following is a summary of the Council's meeting:

Meeting—November 18, 2024:

The Council held its first meeting of the 2024 interim on November 18, 2024. This meeting was also the inaugural meeting of the Council. Senator Stella G. Pekarsky called the meeting to order and the Council members introduced themselves.¹

Election of Chair and Vice-Chair:

Member introductions were followed by the election of the chair and vice-chair of the Council. Delegate Patrick A. Hope moved to nominate Senator Pekarsky and his motion was seconded, upon which the Commission members voted to appoint Senator Pekarsky as the chair of the

¹ **Members Present:** Senator Stella G. Pekarsky (chair); Delegate Patrick A. Hope (vice-chair); Senator Tara A. Durant; Delegate Laura Jane Cohen; Kathryn Hayfield; Jen Krajewski (Designee for Executive Director Teri Morgan); Conner Cummings; Parthenia Dinora; Ann Flippin; Jaime Hanks; Whitney King; Giovanni Knight; Ethan Long; Mia Louria; rian McCann; Tonya Milling; Rose Nevill.

Members Absent: Delegate Kathy KL Tran; Delegate Phillip A. Scott; Nelson Smith; Karen Shelton; James H. Williams; Superintendent Lisa Coons; Cheryl Roberts; Beth Davis.

Council. Next, Senator Pekarsky, presiding as chair, opened the floor for nominations for vice-chair. Delegate Laura Jane Cohen nominated Delegate Hope and her motion was seconded, upon which the Commission members voted to appoint Delegate Hope as vice-chair of the Council.

Adoption of Virtual Meeting Policy:

Following the election of Senator Pekarsky as chair and Delegate Hope as vice-chair, Hannah Yates, Attorney, gave an overview of the virtual meeting policy proposed for adoption by the Council. Ms. Yates gave an overview of the pertinent provisions of the virtual meeting policy, including requirements and guidelines for virtual participation by individual members and requirements and guidelines for holding an all-virtual meeting for the whole Council. Delegate Hope moved to adopt the proposed virtual meeting policy and the motion was seconded. The Council then unanimously adopted the proposed virtual meeting policy.

Overview of SB 389 (2024 Regular Session):

Julia Bergamini, Attorney, provided an overview of SB 389, the bill patroned by Senator Pekarsky during the 2024 Session of the General Assembly which created Chapter 50.1 (§ 30-329.1 et seq.) of Title 30 of the Code of Virginia, thereby establishing the Council. Ms. Bergamini provided some background on the Autism Advisory Council, noting that it was initially established in 2011 and set to sunset on July 1, 2014 pursuant to Chapter 752 of the Acts of Assembly of 2011, but was subsequently extended until July 1, 2022, at which point it was permitted to expire before being reestablished in its present composition with the passage of SB 389 during the 2024 Session of the General Assembly. Ms. Bergamini proceeded to review the current Council's purpose, scope, membership, and powers and duties, and concluded by noting the Council's current sunset date of July 1, 2027.

Discussion:

Senator Pekarsky, presiding as chair, then invited the members of the Council to discuss policy priorities, relevant issues, and areas of significance on which the Council should focus moving forward. Senator Pekarsky noted that because the first meeting of the Council was held so late in the interim, Council members should place particular focus on consideration of priorities and plans for the Council in the forthcoming 2025 interim.

Delegate Cohen noted that one of her priorities for the upcoming 2025 Session of the General Assembly was to pass legislation to facilitate the ability of students with disabilities enrolling in institutions of higher education to promptly receive the appropriate accommodations by requiring public institutions of higher education to accept as proof of disability for the purpose of receiving accommodations any such student's individualized education plan (IEP), provided that such IEP was adopted and implemented no more than three years prior. Delegate Cohen noted that she was planning on introducing a draft to accomplish this.

Senator Durant spoke in support of the legislation Delegate Cohen planned to introduce. Senator Durant next addressed some priorities for the Council to consider moving forward, including (i) applying for a Medicaid waiver to build and fund a continuum of care with the intent of increasing access to services for those diagnosed with a neurocognitive disability like autism, including community based services and crisis intervention services; (ii) improving protections relating to custodial interrogation for individuals with autism spectrum disorder; and (iii) legislation similar to a program implemented in Massachusetts, referred to as the "Blue Envelope Program", relating to ensuring a safe and understanding environment for individuals with autism spectrum disorder during traffic stops by providing such individuals with a specially designed envelope that contains the driver's essential documents as well as critical communication guidelines specifically developed to guide law enforcement officers in adapting their approach when interacting with a driver who is diagnosed with autism spectrum disorder.

Delegate Hope spoke next, first to voice his agreement with Senator Durant's policy priorities. He then noted that there is significant overlap between several of the issues addressed by the Behavioral Health Commission and those that are relevant to the purpose and work of the Autism Advisory Council. Delegate Hope noted that the Council should try to communicate and coordinate with the Behavioral Health Commission in its activities to reduce duplicative work by either body and ensure any issues relating to autism spectrum disorder that are relevant to the purpose of the Council are addressed primarily by the Council. Delegate Hope noted one issue in particular that the Behavioral Health Commission had been considering that, in the future, would likely be more appropriately handled by the Council: namely, addressing the situation in which individuals who are diagnosed with autism spectrum disorder are placed under a temporary detention order and, as a result of it not always clear to judges when an individual meets the legal criteria, ending up in a state hospital or other state-run facility.

Senator Pekarsky concurred and noted that she would be planning to communicate with the Chair of the Behavioral Health Commission relating to coordinating efforts to ensure that each body deals primarily with the issues more germane to its purpose.

Next, Rose Nevill, beginning by addressing policy initiatives like Massachusetts's Blue Envelope Program and the Commonwealth's law permitting, pursuant to § 46.2-342 of the Code of Virginia, individuals who are diagnosed with autism spectrum disorder to include on their driver's license an indication of their diagnoses. Ms. Nevill emphasized the importance of the Council considering various perspectives on these types of policy initiatives, noting that some individuals may be hesitant to take advantage of the law due concerns that identifying themselves as being diagnosed with autism spectrum disorder on their driver's license and other such documents could result in adverse treatment or social shame or stigma. Ms. Nevill also noted, in relation to this issue, that the Council should also consider the importance of ensuring community members, law enforcement officers, and other first responders are appropriately informed and educated relating to the needs of and interacting with individuals with autism spectrum disorder.

Parthenia Dinora noted that the Council, moving forward, should prioritize outreach to adults diagnosed with autism spectrum disorder in carrying out its powers and duties to ensure that their perspectives are considered and factored into the Council's work. Brian McCann signaled his agreement, adding that, in particular, the Council should be careful not to overlook the perspectives of individuals who are diagnosed with autism spectrum disorder and who are nonverbal. Ethan Long agreed with Mr. McCann and emphasized that the Council should ensure that it considers and includes the needs and perspectives of individuals diagnosed with autism spectrum disorder who have high support need and should, in its work, always be conscientious of how wide and diverse autism spectrum disorder is to ensure that no one's perspectives or needs are being overlooked.

Giovanni Knight spoke on the importance of intersectional considerations and how various factors including race, ethnicity, gender, and other mental health conditions or disabilities influence the perspectives and needs of individuals diagnosed with autism spectrum disorder.

The Council members continued to discuss the issues and priorities addressed, emphasizing the importance of these considerations and signaling their agreement. Senator Pekarsky concluded the Council's discussion by noting that, when looking forward to and preparing for the 2025 interim, the Council members should consider improving and developing coordinated resources and data on issues relevant to the Council's purpose and work, noting that coordinated and robust data would be instrumental to the work of the Council in the forthcoming interim.

Public Comment:

After the Council members concluded their discussion, Senator Pekarsky opened the floor up to public comment. Two individuals were present to give public comment.

The first of whom was Brian Kelmar, President of Decriminalize Developmental Disabilities. Mr. Kelmar spoke on the significance of the issue of individuals diagnosed with autism spectrum disorder, including minors, getting caught up in the criminal justice system and subject to punitive procedures and treatments when the circumstances actually were a result of a crisis situation arising from their developmental disability. Mr. Kelmar in particular highlighted the necessity of prioritizing policies and legislation aimed at mitigating the incidence of such individuals with autism spectrum disorder being detained, ending up in jail, or incarcerated as a result of mishandling and misunderstanding how to interact with and address individuals with autism spectrum disorder, particularly in high-stress situations or when they are in crisis.

The second and final speaker during the public comment portion of the meeting was Theresa Champion with the Virginia Autism Project. Ms. Champion discussed several issues relating to various issues and topics the Council members addressed throughout the meeting. Ms. Champion emphasized that the purpose for which the Council was established and the nature of its duties necessitated having an independent, paid staff that possessed the subject matter expertise

necessary to do the requisite level of research, as opposed to the Council's current staff, who, pursuant to current law, is provided by the Division of Legislative Services.

Closing Remarks and Adjournment:

Senator Pekarsky then delivered her closing remarks before entertaining a motion to adjourn. The motion was made and seconded and the Council adjourned.