SB176/HB888 Workgroup on Placements in Virginia for People with Neurocognitive Disorders and Neurodevelopmental Disabilities

Secretary of Health and Human Resources
Thursday, August 15, 2024 | 10:00 AM – 12:30 PM
Location; DARS with Virtual Option

MINUTES – Meeting Two
Identifying Supports and Services Needed in the System

In-Person Attendance:
Leah Mills, Deputy Secretary of Health and Human Resources
Nelson Smith, Commissioner of DBHDS
Braden Curtis, Chief Deputy Commissioner DBHDS
Trevor Moncure, Commonwealth Strategy on Behalf of Psychiatric Society of Virginia (PSV)
Dr. Adam Kaul, Psychiatric Society of Virginia
Lucy Cantrell, The Arc of Virginia
Terri Morgan, Virginia Board for People with Disabilities
Brian Unwin, Carilion
Julie Dime, Virginia Hospital and Health Care Association
Karen Garner, Alzheimer's Association
Josh Myers, Alzheimer's Association
Lyndsy Robinson, Alzheimer's Association
Jason Young, Community Brain Injury Services
Heather Norton, Deputy Commissioner of Community Services DBHDS
Jennifer Fidura, Virginia Network of Private Providers
Judy Hackler, Virginia Assisted Living Association
Aimee Peron Seibert, Commonwealth Strategy on Behalf of VACEP
Catherine Harrison, Department of Aging and Rehabilitative Services
Lauren Webb, Virginia College of Emergency Physicians

Virtual Attendance:
Louis Hagopian, Kennedy Krieger Institute
Rachel Ernest, The Faison Center
Senator Barbara Favola, Behavioral Health Commission
Ann Bevan, Department of Medical Assistance Services
Delegate Vivian Watts, Behavioral Health Commission and Criminal Law Sub Committee
Johnathan Green, Office of the Executive Secretary
Martin Mash, VOCAL Virginia
Sandy Bryant, Mt. Rogers Community Services Board
Becca Herbig, Disability Law Center of Virginia
Elizabeth Hobbs, Virginia Sheriffs' Association
Keith Hare and April Payne, Virginia Health Care Association

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Deborah Dashiell, Western Tidewater Community Services Board
Yukiko Dove, Parent Advocate
Ben Breaux, Self-advocate
Jennifer Faison, Virginia Association of Community Services Boards
Autumn Richardson, Richmond Behavioral Health Authority

Welcome and Review of Meeting One – HHR Deputy Secretary Leah Mills

Deputy Secretary Mills reviewed the workgroup charge and essential questions that the workgroup must consider. She reviewed key points of discussion from the first meeting including the lack of options for short-term crisis stabilization and long-term care for individuals with neurodevelopmental disabilities (NDD) and neurocognitive disorders (NCD) experiencing behavioral challenges. She highlighted the time limitation of the ECO process, which does not permit a comprehensive evaluation. She noted that differentiating between crises caused by NDD/NCD versus mental health conditions is crucial for appropriate intervention and she encouraged the workgroup, when making recommendations on the reenactment of the legislation, to consider the extent to which prescreeners have the capacity to accurately determine the cause of a behavioral health crisis. Finally, she emphasized that choice, dignity, and least restrictive environment are guiding principles for the workgroup.

Alternatives to state hospital placement

Services for individuals with developmental disabilities

Louis Hagopian, PhD, Kennedy Krieger Institute – Treatment of individuals with neurobehavioral disorders (Inpatient and Intensive Outpatient Programs)

Dr. Hagopian shared the mission of the Kennedy Krieger Institute (KKI), which is to free individuals and their families from the burdens of challenging behavior so they can live their lives. Individuals receiving services should make choices to the fullest extent of their abilities and receive the least restrictive intervention necessary.

Dr. Hagopian emphasized that challenging behavior in individuals with NDD is heterogeneous in and requires a range of individualized interventions. Assessment and treatment require specialized resources including appropriate clinical expertise, staff adequacy and training, policies and procedures to ensure safety and quality, and specialized facilities to effectively manage and support individuals' needs. He also highlighted the importance of distinguishing between managing behavior versus treating behavior.

KKI uses a neurobehavioral model of care across all programs recognizing multiple determinants of behavior. Neurobehavioral programs include consultation with hospitals and schools, outpatient, intensive outpatient, and inpatient treatment. Multiple factors are considered when determining the appropriate level of service, including severity of behavior, resistance to treatment, current and past services, current environment, services available locally, medical and nursing needs, medication, caregiver goals and priorities, and insurance coverage. Dr. Hagopian shared case examples demonstrating successful treatment using this model of care.

KKI's neurobehavioral continuum of care includes:

- Outpatient: For moderate severity cases, where the individual is safe to transport, and few services have been provided previously. Provides treatment 2 hours/week over 3-4 months.
- Intensive outpatient: For more severe cases with treatment resistance, where the individual has had prior outpatient services and is safe to transfer to the clinic, though family involvement may be more challenging. Offers intermediate care with 5 hours/day over 3 weeks.
- Inpatient: Reserved for the most severe cases with high treatment resistance, significant injuries (such as self-blindness or permanent scarring), where the individual is not safe for clinic transfer and may require pharmacological intervention. Involving behavioral therapy and medical intervention for up to 5 months.

Dr. Hagopian noted that training is needed to ensure competency include didactic instruction, annual competency assessments, physical demonstration of skills, and ongoing feedback and coaching. He also noted that caregivers should be trained to high levels of proficiency. Finally, Dr. Hagopian expressed that collaboration should occur across all clinical programs and external entities to support assessment of individuals' needs and inform service planning (e.g., state agencies, schools, and insurance companies).

Stakeholder Perspective, The Arc – A parent shares their experience of a time that the crisis services helped and another time that they did not help.

Ann Flippin with the Autism Society of Virginia shared her experience as a sibling and guardian of her adult brother who has Autism and has experienced multiple behavioral health crises and psychiatric hospitalizations. She highlighted challenges including emergency responders not listening to caregivers, use of sedation to temporarily stabilize, discharge without an appropriate discharge plan, and lack of access to support post-discharge resulting in rehospitalization.

Ms. Flippin also shared a recent experience supporting another family. The emergency room could not stabilize their loved one during a crisis, and private hospitals were unwilling to admit him due to his Autism. The family was told that, if he was committed, he would have to go to a state facility and there are no alternative placements available for discharge. She hypothesized that a driving factor may be an increasing population of aging parents who need more support.

Ms. Flippin asked the workgroup to consider, “What does success look like?”. She encouraged the workgroup to prioritize listening to families, caregivers, and support staff. She also encouraged recommendations that focus on training all professionals involved in crisis response (e.g., law enforcement, emergency service workers, emergency room staff) in how to support individuals with co-occurring developmental disabilities and behavioral health challenges and identifying spaces with quick access to care for individuals in crisis.

Services for individuals with neurocognitive disorders

Catherine Harrison, DARS – Serving Individuals with Brain Injuries, Dementia, and Co-Occurring Disorders

Catherine Harrison reviewed studies demonstrating an increased risk of dementia for individuals diagnosed with certain psychiatric disorders and the heightened prevalence of brain injury in individuals with behavioral health and substance use disorders. She emphasized that behaviors and symptoms can stem from a variety of diagnoses but that, during a crisis, the cause is not always known or readily distinguishable. She cautioned that without access to appropriate crisis and long-term care placements, individuals can get stuck in emergency departments, become involved in the criminal justice system, or homeless.

Ms. Harrison noted that individuals with NCD have a wide spectrum of symptom complexity but that the majority can and are being served successfully in existing standard Home and Community Based Settings (HCBS) and Long-Term Care (LTC) settings. However, individuals with severe behavioral and psychological symptoms (either due to a single but intensive neurocognitive disorder diagnosis or due to the interplay of co-occurring conditions) may need more intensive or alternative services that are not permitted, offered, reimbursed, or safe for other residents and staff in standard HCBS or LTC settings. Common barriers include aggressiveness, active substance use, lack of family support, and criminal records. Some individuals' income and/or assets disqualify them from Medicaid LTC but are also too low to cover costs privately. Other individuals may not meet Virginia's Medicaid nursing facility level of care but cannot be safely served in other HCBS or LTC settings.

Finally, Ms. Harrison reviewed current services offered by DARS, including Brain Injury Case Management and Dementia Care Coordination, In-Home or Home-Based Services, and Decision-Making through the Public Guardianship & Conservatorship Program. She emphasized that none are designed to serve as Crisis Services or sustainable LTC Services; all had limited funding, and services are not guaranteed; and all had access delays (e.g., waitlists, assessments, and approval processes). She noted that case management, care coordination, and substituted decision making are not "hands-on" care services. Brain Injury Case Management and Dementia Care Coordination are not 24-hour services, and Dementia Care Coordination is not available in all areas of Virginia. Similarly, In-Home or Home-Based Services are not available 24/7 and are not available in all areas of Virginia.

Ms. Harrison concluded by supporting recommendations to scale up DBHDS pilot programs presented at the first meeting as well as the discussion of developing new specialized crisis services and long-term intensive placements. She also stated that the system must invest in comprehensive training and increasing staffing levels.

Stakeholder Perspectives:

Jason Young – Community Brain Injury Services

Jason Young and his colleagues presented a case management summary of an active case involving a veteran experiencing homelessness with PTSD, brain injury, substance use disorder, and multiple co-occurring medical conditions. He received various housing and behavioral health services from multiple community providers over the past year and experienced multiple medical and psychiatric hospitalizations. He had multiple suicide attempts resulting in serious harm to self, and his last attempt resulted in arrest and multiple felony charges. He is now at a state hospital for competency restoration.

The case managers emphasized a significant lack of communication among the community support team private and public psychiatric facilities and that discharge plans were incoherent. They noted the systemic issue of arresting individuals experiencing behavioral health crisis and suggested that the workgroup consider amending code to require all inpatient psychiatric facilities to communicate with community case management teams.

DBHDS Commissioner Nelson Smith noted the role of the DBHDS enterprise data warehouse will play in supporting care coordination of patients. He also highlighted parallels between the case example this team shared and lessons learned from the Safe and Sound Taskforce. For both, communication was the biggest systemic barrier to successfully supporting people in need of and receiving care. Deputy Secretary Mills added that it is crucial to investigate why information is not shared effectively. Keeping families at the forefront of care and ensuring they are actively involved and informed throughout the process is essential.

Karen Garner – The Alzheimer's Association

Karen Garner shared her lived experience as a spouse of an individual with early onset Alzheimer's. While receiving respite care from family, Ms. Garner's husband's condition worsened, and he was taken by law enforcement to a hospital and placed in a psychiatric hold for a week. He permanently regressed after that episode of treatment before his death a year later.

Ms. Garner recommended that the workgroup emphasize in its report that dementia patients, and people with other NCD and NDD, have distinct needs that cannot be treated the same when they experience crisis. She noted that there are specialized cancer case management teams, but no parallel services exist for dementia patients. She also recommended that the workgroup identify means of ensuring that caregivers have the right to stay with individuals during crisis situation.

Deputy Secretary Mills noted that legislation to address parental notification in times of crisis that passed during the last General Assembly session may address some of those problems by defining when providers must permit family members to remain with individuals in crisis.

Building Capacity and Competency

Rachel Ernest – The Faison Center

Rachel Ernest suggested that the workgroup focus on the need to identify a location other than hospitals or jails for individuals to stabilize while their medication, home environment, etc. are being adjusted. Locations need to have staff who are specialized and trained to support individuals with neurodevelopmental disabilities and facilities adapted to support them. These spaces need to be open and staffed at all times.

Judy Hackler – Virginia Assisted Living Association (VALA)

Judy Hackler highlighted the increasing demand for long-term care due to the rapidly aging population. She emphasized the need for a continuum of alternatives to hospitals noting that memory care can be included in both assisted living and nursing homes. She said that, as compared to nursing homes, assisted living has more licensed providers and resident capacity with a lower average provider size and is also less expensive. Ms. Hackler noted that Virginia had an Alzheimer's Waiver Assisted Living Waiver that terminated in 2018 and that Virginia is one of 12 states that does not have an approved Medicaid waiver for assisted living services. She also noted how veterans are impacted by capacity limitations. Ms. Hackler recommended that the workgroup identify additional funding sources and provide training to licensed providers on available resources to support challenging placements (i.e., DAP funding, social worker supports).

Public comment

Brian Kelmar, Parent Advocate
Mr. Kelmar is a parent of a son with Autism. He emphasized the importance of families being part of the solution and differentiating recommendations for addressing short-term issues with initial response vs. long-term challenges (e.g., supports for avoiding crisis and alternative long term placements). He recommended that the workgroup should work to develop effective interventions that support individuals and families and prevent behaviors from being criminalized due to inadequate or inappropriate care and services.

Jeannine Rosado, Parent Advocate
Ms. Rosado, the mother and legal guardian of an adult son with Autism, shared her lived experience supporting her son. He was placed under a TDO, and a bed could not be found for him in a private or public facility. He was charged with multiple counts of felony assault of a law enforcement officer, and the family was told that incarceration was the only option to access care. He was eventually taken to Central State Hospital through the forensic system. The family has spent a significant amount of money in legal fees as a result of this incident.

Lyndsy Robinson, Alzheimer's Association advocate with lived experience
Ms. Robinson shared her experience supporting her father with Alzheimer's. He experienced a crisis that resulted in law enforcement response and hospitalization. He was administered medication that led to severe side effects, and she was unable to see her father for four days due to those side effects. He was placed into a nursing home without memory care specialization. He fell multiple times while at the facility and passed away as a result of his injuries.

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Dr. Badr Ratnakaran (Dr. B), Psychiatric Society of Virginia
Dr. B specializes in treating dementia and other NCD. He highlighted a significant shortage of resources and specialists in this field. He recommended that the workgroup consider incorporating more content on geriatrics in CIT Training for law enforcement similar to what is used in California. He expressed concerns that reenactment of the legislation would remove a safety net without identifying alternatives for patients in crisis who are a danger to self and others. He emphasized the need for specialized spaces equipped to manage complex behaviors associated with severe dementia while providing a safe environment for patients and staff.

Next Steps/Adjourn

Deputy Secretary Leah Mills reviewed next steps for the workgroup asking everyone to send ideas for recommendations to Josie Mace as this would be the focus of the next meeting.

Workgroup enactment language:

"That the Secretary of Health and Human Resources shall convene a work group of relevant stakeholders, including representatives from local community services boards, the Virginia Hospital and Healthcare Association, and the Office of the Executive Secretary of the Supreme Court of Virginia to:

(i) evaluate the current availability of placements for individuals with neurocognitive disorders and neurodevelopmental disabilities who would otherwise be placed in state psychiatric hospitals;
(ii) identify and develop placements and services other than state psychiatric hospitals that would better support such individuals, especially individuals whose behaviors or symptoms are solely a manifestation of such disorders and disabilities, including through enhanced Medicaid reimbursements and a Medicaid waiver for individuals with neurocognitive disorders;
(iii) specify any additional funding or statutory changes needed to prevent inappropriate placements of such individuals in state psychiatric hospitals;
(iv) provide recommendations for training of magistrates and community services boards related to the implementation of this act; and
(v) report the work group's findings and recommendations to the Chairmen of the House Committee on Appropriations, the Senate Committee on Finance and Appropriations, the House Committee on Health and Human Services, and the Senate Committee on Education and Health by November 1, 2024.