

# COMMONWEALTH of VIRGINIA

# Office of the Governor

Janet Vestal Kelly Secretary of Health and Human Resources

November 22, 2024

To: The Honorable L. Louise Lucas Chair, Senate Finance and Appropriations Committee

> The Honorable Ghazala F. Hashmi Chair, Senate Education and Health Committee

The Honorable Luke E. Torian Chair, House Appropriations Committee

The Honorable Mark D. Sickles Chair, House Health and Human Services Committee

From: Janet V. Kelly Secretary, Secretary of Health and Human Resources

RE: Chapter 579 & 696, 2024 Virginia Acts of Assembly (HB888/SB176)

Chapters 579 and 696 of the 2024 Virginia Acts of Assembly direct the Secretary of Health and Human Resources to convene a workgroup to evaluate placements for individuals with neurocognitive disorders and neurodevelopmental disabilities who would otherwise be placed in state psychiatric hospitals, identify and develop alternative placements and services, specify funding or statutory changes needed to prevent inappropriate placements, and provide recommendations for training related to implementation of the act:

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

Patrick Henry Building • 1111 East Broad • Richmond, Virginia 23219 (804) 786-2211 • TTY (800) 828-1120 www.governor.virginia.gov 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.

In accordance with this item, please find enclosed the report of the HB888/SB176 2024 Workgroup on Placements for People with Neurocognitive Disorders and Neurodevelopmental Disabilities. Staff are available should you wish to discuss this request.

cc: Commissioner Nelson Smith, Department of Behavioral Health and Developmental Services

# HB888/SB176 2024 Workgroup on Placements for People with Neurocognitive Disorders and Neurodevelopmental Disabilities

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# Introduction

In December 2023, the Joint Legislative Audit and Review Commission (JLARC) reported on Virginia's State Psychiatric Hospitals.<sup>1</sup> JLARC found that individuals with a primary diagnosis of neurocognitive disorders and neurodevelopmental disabilities accounted for 10 percent of state psychiatric hospital discharges in FY 2023. It should be noted that this total only accounts for primary diagnosis, and some of the individuals included had co-occurring mental health diagnoses. JLARC found that individuals with neurocognitive and/or neurodevelopmental disorders had longer lengths of stay in state psychiatric facilities. Staff reported they lacked expertise to care for these patients and were at higher risk of victimization. The first four recommendations in the JLARC report address these findings.

HB 888 (Watts) and SB 176 (Favola) were passed during the 2024 General Assembly Session in response to the JLARC findings. Chapters 579 and 696 of the 2024 Virginia Acts of Assembly respond to the recommendations of the JLARC report. These amendments are subject to reenactment by the General Assembly during the 2025 Session. In addition to other changes, the amendments would specify that for the purpose of civil commitments and temporary detention orders (TDOs), behaviors and symptoms that manifest from a neurocognitive disorder or neurodevelopmental disability are excluded from the definition of mental illness and are, therefore, not a basis for an individual to be placed under a TDO or committed involuntarily to an inpatient psychiatric hospital.

In addition, Chapters 579 and 696 direct the Secretary of Health and Human Resources to convene a workgroup to evaluate availability of current placements for individuals with neurocognitive disorders and neurodevelopmental disabilities who would otherwise be placed in state psychiatric hospitals, identify and develop alternative placements and services, specify funding or statutory changes needed to prevent inappropriate placements, and provide recommendations for training related to implementation of the language subject to reenactment.

# Overview of Activities of the HB888/SB176 2024 Workgroup on Placements for People with Neurocognitive Disorders and Neurodevelopmental Disabilities

The charge for the workgroup was broad, covering service for individuals with mental illness, brain injury, dementia, autism and other developmental disabilities. There are many specialty populations included under these populations. Their care needs vary significantly and are often medically complex and unique to the individual.

The workgroup met five times from August to October of 2024. Workgroup membership extended far beyond those required in the legislation to ensure the expertise and perspectives were present to deliver impactful recommendations. In addition to executive and legislative membership, the workgroup included family members, law enforcement, advocates, providers

<sup>&</sup>lt;sup>1</sup> https://bhc.virginia.gov/documents/Revised%20Presentation%20-%20JLARC%20psych%20hospital%20study.pdf

and other experts in the fields of behavioral health, brain injury, dementia and developmental disabilities including autism. Membership included representatives from the following agencies and organizations:

- The Office of the Secretary of Health and Human Resources
- Senator Favola
- Delegate Watts
- DBHDS
- DARS
- DMAS
- Office of the Executive Secretary of the Supreme Court of Virginia
- The Arc of Virginia
- Behavioral Health Commission
- Decriminalize Developmental Disabilities
- disAbility Law Center of Virginia
- Brain Injury Association of Virginia
- The Faison Center

- Family Members
- Mental Health Virginia
- NAMI-VA
- Neuro-Restorative
- Partnership for People with Disabilities
- VA Alliance of Brain injury Service Providers
- VA Association of Chiefs of Police
- VA Association of Community Services Boards
- VA Autism Project
- VA Health Care Association
- Virginia Hospital and Health Care Association
- VA Network of Private Providers
- VA Sheriffs Association
- Vocal Virginia

The workgroup received presentations from a wide array of stakeholders. Family members and caregivers of individuals with neurodevelopmental and neurocognitive disorders shared their lived experiences through presentations and participation in public comment. Advocacy organizations including The Arc of Virginia, The Virginia Autism Project, and the Virginia Alzheimer's Association also presented. Public and private provider associations provided presentations including the Virginia Association of Community Services Boards, Virginia League of Social Service Executives, Community Brain Injury Services, Virginia Hospital and Healthcare Association, Virginia Healthcare Association, and Virginia Assisted Living Association. The Kennedy Krieger Institute, the Faison Center, and NeuroRestorative gave individual provider perspectives. State agencies including the Department of Behavioral Health and Developmental Services (DBHDS), Department of Aging and Rehabilitative Services (DARS), and Department of Medical Assistance Services (DMAS), and Office of the Executive Secretary (OES) Department of Magistrate services also provided presentations. Please see the Appendices for the workgroup membership list, information submitted by stakeholder organizations, meeting minutes, and presentation materials.

#### **Definition of Neurocognitive and Neurodevelopmental Disorders**

The Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5) of the American Psychiatric Association defines diagnostic criteria for neurodevelopmental and neurocognitive disorders.

Neurocognitive disorders are characterized by a decline from a previously attained level of cognitive functioning. Mild and major neurocognitive disorders have various causes including Alzheimer disease, cerebrovascular disease, Lewy body disease, frontotemporal degeneration, traumatic brain injury, infections, and alcohol abuse. Major neurocognitive disorder is

characterized by dementia. Mild neurocognitive disorder includes some level of memory impairment and decline in ability to perform everyday activities, although individuals are still able to perform these activities without assistance, and difficulties with language, perceptual-motor and social skills. These impairments are more significant than age related changes experienced by the neurotypical population. Mood disturbances, including sudden increases in depression, bipolar-like mood swings or disinhibition, agitation, anxiety, or a sudden onset of apathy or dysthymia are often early indicators of the cognitive decline. Certain psychiatric disorders are also associated with an increased risk of dementia.<sup>2 3 4 5</sup>

Neurodevelopmental disorders are a group of conditions with onset in the developmental period, often before a child enters grade school, characterized by developmental deficits that produce impairments of personal, social, academic, or occupational functioning. The DSM-5 includes the following within its definition of neurodevelopmental disorders:

- Intellectual Disability
- Autism Spectrum Disorder
- Global Developmental Delay
- Communication disorders: language disorder, speech sound disorder, social (pragmatic) communication disorder, and childhoodonset fluency disorder (stuttering)
- Attention Deficit-Hyperactivity Disorder (ADHD)
- Specific Learning Disorders
- Neurodevelopmental motor disorders: developmental coordination disorder, stereotypic movement disorder, and tic disorders

In Virginia, 40 percent (females) /60 percent (males) of individuals with a developmental disorder (DD) have a mental health condition and/or behavioral support needs and approximately 50 percent of all individuals with DD are on at least one psychiatric medication for a mental health condition.<sup>6</sup>

### Review of Virginia Initiatives to support individuals with Neurodevelopmental Disabilities and Neurocognitive Disorders and Behavioral Challenges Department of Justice Settlement Agreement

Section III.C.6.a.i-iii of the 2012 Department of Justice (DOJ) Settlement Agreement with the Commonwealth requires Virginia to implement a statewide crisis system for individuals with intellectual and developmental disabilities. Under this system the Commonwealth must provide timely and accessible support to individuals in crisis, crisis prevention services and planning, and in-home and community-based crisis services to prevent removal from current placement

<sup>&</sup>lt;sup>2</sup> Mo, et al. (2023). Psychiatric Disorders Before and After Dementia Diagnosis. *JAMA Network Open*. doi:10.1001/jamanetworkopen.2023.38080

<sup>&</sup>lt;sup>3</sup> Richmond-Rakerd, et al. (2022). Longitudinal associations of mental disorders with dementia. *JAMA Psychiatry*, doi: 10.1001/jamapsychiatry.2021.4377

<sup>&</sup>lt;sup>4</sup> Stafford, et al. (2022). Psychiatric Disorders and risk of subsequent dementia. *International Journal of Geriatric Psychiatry*. doi: 10.1002/gps.5711

<sup>&</sup>lt;sup>5</sup> Brown & Wolf. (2018). Estimating the prevalence of serious mental illness and dementia diagnosis among

Medicare beneficiaries in the health and retirement study. *Research on Aging*. doi: 10.1177/0164027517728554. <sup>6</sup> Lineberry S et al. (2023) Co-occurring mental illness and behavioral support needs in Adults with Intellectual and Developmental Disabilities. *Community Mental Health Journal*. doi: 10.1007/s10597-023-01091-4

whenever practicable. There are 22 compliance indicators focused on crisis prevention including crisis assessments in the community, behavioral services, direct service provider availability, and psychiatric hospital admissions/discharges. There are seven compliance indicators related to mobile crisis and another seven focused on crisis stabilization including community therapeutic home availability, out of home prevention, and residential services. The Commonwealth of Virginia DOJ Settlement Agreement Library may be referenced for more information on settlement agreement requirements, compliance indicators, and reporting.<sup>7</sup>

### **General Assembly Workgroups and Reports**

In 2021, the General Assembly directed the Secretary of Health and Human Resources to convene a workgroup to make recommendations for enhanced services for individuals with dementia to reduce preventable hospitalizations.<sup>8</sup> The General Assembly also directed DBHDS to report on the state hospital discharge process which included analysis and recommendations for supporting special populations.<sup>9</sup> With the support of the General Assembly, DBHDS began implementing programs consistent with the recommendations of the reports. Current programs include Wytheville (Carrington Memory Care Partnership and Mt. Rogers Wythe House), Suffolk (Western Tidewater Dementia Programs), Waverly and Chilhowie (Nursing Home Partnerships), and Northern Virginia (RAFT Dementia Support Program). DBHDS reported on the implementation of these programs in quarterly reports<sup>10</sup> and an annual report submitted to the General Assembly in June 2022.<sup>11</sup> While these programs are ongoing, due in part to the li, they have only been able to serve a small proportion of the individuals with dementia who are referred for admission to state hospitals. Please see the Appendix for an overview of Temporary Detention Order and Involuntary Admission process and Programs Supporting People with Neurodevelopmental Disabilities and Neurocognitive Disorders Experiencing Behavioral Health Challenges.

In 2022, the General Assembly directed the Department of Medical Assistance Services (DMAS) to convene a workgroup to develop a plan for a neurobehavioral science unit and a waiver program for individuals with brain injury and neurocognitive disorders.<sup>12</sup> A summary of the work and final proposals of the Brain Injury Services Steering Committee was presented at their last meeting in May of 2023.<sup>13</sup> Findings from the associated rate study for the proposed continuum of services for individuals with brain injury and neurocognitive disorders included

<sup>&</sup>lt;sup>7</sup> Commonwealth of Virginia DOJ Settlement Agreement Document Library.

https://dojsettlementagreement.virginia.gov/.

<sup>&</sup>lt;sup>8</sup> DBHDS. (2021). Report on the Item 321 N.4 of the 2021 Appropriations Act Dementia Services Workgroup. https://rga.lis.virginia.gov/Published/2021/RD801/PDF

<sup>&</sup>lt;sup>9</sup> DBHDS. (2022). Report on Chapter 249 of the 2021 Acts of Assembly (SB1304) Report on the State Hospital Discharge Process. https://rga.lis.virginia.gov/Published/2022/RD31/PDF.

<sup>&</sup>lt;sup>10</sup> DBHDS. (2022). Report on Item 320 CC.2 Report on the Establishment of Census Pilot Projects https://rga.lis.virginia.gov/Published/2022/RD280/PDF

<sup>&</sup>lt;sup>11</sup> DBHDS. (2022). Report on the Development of Programs for Individuals with Dementia Served by State Hospitals https://rga.lis.virginia.gov/Published/2022/RD676/PDF

<sup>&</sup>lt;sup>12</sup> DMAS. (2022). Report on Planning for the Development of Services for Individuals with Brain Injuries and Neuro-Cognitive Disorders. https://rga.lis.virginia.gov/Published/2022/RD630/PDF

<sup>&</sup>lt;sup>13</sup> https://www.dmas.virginia.gov/media/5825/steering-commitee-deck-05-02-2023.pdf

targeted case management under the state plan, 1915 (c) Home and Community Based Services waiver, and Neurobehavioral Treatment Facility was presented in July of 2023.<sup>14</sup> Of the services proposed, only Targeted Case Management for individuals with Traumatic Brain Injury was implemented in Virginia Medicaid in 2024. Please see the DMAS Overview presentation in the Appendix for additional information. During the 2024 General Assembly Session, bills were introduced but did not pass that would have directed DMAS to seek the appropriate authority to add neurobehavioral and neurorehabilitation facilities as an alternative institutional placement for individuals requiring traumatic brain injury treatment. The bills would have also directed DMAS to seek authority to modify the existing 1915 (c) waiver or create a new waiver to administer home and community-based services for qualifying individuals with traumatic brain injury and neurocognitive disorders.<sup>15</sup> <sup>16</sup>

# **Key Findings**

Through staff research, valuable presentations, and extensive stakeholder perspectives, the workgroup made key overarching findings that helped guide its recommendations. These findings include:

- The workgroup expressed concerns about unintended consequences resulting from changing the definition of mental illness as required in HB888/SB176. The workgroup commends the patrons for efforts to address inappropriate placement of individuals with neurocognitive and neurodevelopmental disabilities in state psychiatric hospitals. Unfortunately, state hospitals may be the only option for some individuals when in crisis. Although state hospitals are not suitable for those whose behavioral health crisis stems from a neurocognitive disorder or neurodevelopmental disability, the alternatives outside of state hospitals are limited for these populations.
- Data from Virginia's DD Waiver population indicated that almost 70 percent of individuals with ID/DD have a co-occurring behavioral health condition that requires specialized behavioral health treatment.
- Individuals with neurodevelopmental disabilities and neurocognitive disorders with behavioral health challenges lack adequate access to long-term care and support services and crisis services with the training and expertise to support them remaining in their current placement. When in-patient care is needed, individuals in these populations generally lack access to services and clinicians with the specialization required to meet their needs.
- The current workforce does not have the necessary expertise to effectively support these individuals. By strengthening the skills and capabilities of existing staff, we can significantly increase the number of placements equipped to care for them at all levels of the care continuum.

bin/legp604.exe?ses=241&typ=bil&val=HB593

<sup>&</sup>lt;sup>14</sup> DMAS. (2023). Virginia Brain Injury Services Rate Study Final Presentation.

https://www.dmas.virginia.gov/media/6359/steering-committee-07-11-2023.pdf

<sup>&</sup>lt;sup>15</sup> Virginia General Assembly House Bill 593. 2024 Session. Neurobehavioral and Neurorehabilitation Facilities; Waiver Services for Individuals with Brain Injury. https://legacylis.virginia.gov/cgi-

<sup>&</sup>lt;sup>16</sup> Virginia General Assembly House Bill 1064. 2024 Session. https://legacylis.virginia.gov/cgibin/legp604.exe?ses=241&typ=bil&val=HB1064

- Communication barriers, especially during a behavioral health crisis, can result in individuals with neurodevelopmental disabilities or neurocognitive disorders being inappropriately placed or kept longer than necessary in state hospitals or other facilities such as jails. Providing adaptive communication support is essential to ensure they receive appropriate care and placement.
- Caregivers play a critical role in supporting individuals in the least restrictive settings, advocating for their needs, and preventing unnecessary placements in state facilities. To continue fulfilling this vital role, caregivers and legal decision-makers must receive comprehensive information and resources so they can effectively support the individual's behavioral health crisis. Strengthening this support network is essential to ensuring the best outcomes for those they serve.
- Training certified prescreeners and magistrates alone cannot ensure the successful implementation of HB888/SB176. The clinical complexity of determining whether an individual's behavior stems from a neurodevelopmental disability, a neurocognitive disorder, or a mental illness goes beyond what training can address—especially given the current qualifications required for prescreeners and the strict timeline for completing Temporary Detention Order (TDO) evaluations during the Emergency Custody Order (ECO) period. Additionally, without immediate access to appropriate services that meet the unique needs of this population, no amount of training will fill this critical gap.

# Recommendations

# **Critical Issues and Gaps Must be Addressed**

Individuals whose behaviors are a sole manifestation of a neurodevelopmental disability or neurocognitive disorder may still be a significant danger to self and/or others and require high intensity behavioral health services including in-patient care. Individuals within this population are placed in state facilities as a last resort to maintain their safety and the safety of their caregivers when it is determined that no alternative safe placement is available. Nearly all private inpatient facilities in the state have neurodevelopmental disability and neurocognitive disorder as an exclusionary criteria for admission. Because of these criteria, individuals with these conditions cannot receive care in private inpatient facilities notwithstanding a diagnosed co-occurring mental illness, further causing negative impact to the individual and caregiver seeking behavioral health support.

**Recommendation 1**: The workgroup commends the patrons of HB 888/SB176 for introducing legislation to address the inappropriate placement of individuals with neurocognitive and neurodevelopmental disabilities in state psychiatric hospitals. The workgroup agrees that state psychiatric hospitals are not suitable for individuals whose behavioral health crisis stems from their neurocognitive disorder or neurodevelopmental disability, rather than a mental illness. A broader continuum of care, including more community-based options, is needed. However, there are limited alternatives outside of state hospitals for individuals with neurocognitive or neurodevelopmental disabilities is closed to individuals with neurocognitive or neurodevelopmental disabilities, there may be no other

options for individuals in crisis and their families. State hospital placement is their last option. Therefore, the workgroup recommends that HB888/SB176 not be reenacted at this time. The recommendations contained in this report are steps towards improving existing services and developing new services which could help divert individuals from state psychiatric hospital placement. Until these types of services better cover Virginia, the workgroup finds re-enacting this legislation would likely not have the desired effect for several reasons:

- Changing the statutory definition of mental illness would require certified prescreeners and magistrates to determine whether an individual's behaviors are the sole manifestation of a neurodevelopmental disability or neurocognitive disorder during the ECO and TDO process.
- TDO evaluations must occur within the eight-hour ECO period. The purpose of the TDO evaluation is to determine if an individual meets Virginia's code requirements for involuntary civil commitment, not to conduct a comprehensive behavioral health diagnostic assessment. Further, prescreeners are not required to be licensed clinicians and cannot make complex diagnostic decisions during a crisis evaluation.
- Many individuals who are evaluated are not previously known to the CSB prescreener evaluating them, and medical and psychiatric information is not accessible at the time of evaluation. Even if that history is accessible, individuals with underlying neurodevelopmental disabilities or neurocognitive disorders may not yet have a formal diagnosis.
- Some individuals with neurodevelopmental disabilities and neurocognitive disorders with behavioral challenges may have co-occurring mental illnesses that have not been formally diagnosed. It may not be possible to determine during the short ECO period whether their behaviors are a sole manifestation of these conditions. Making this determination is complex and time intensive and requires comparing their behaviors to their unique baseline.

# Build a Sustainable and Comprehensive Continuum of Care

The workgroup identified need to increase access to services for individuals with neurodevelopmental disabilities and neurocognitive disorders experiencing behavioral challenges that would prevent or provide alternative treatment locations to state facilities. Such services include specialized high-intensity behavioral health services for individuals needing a higher level of care, crisis services, and specialized services and supports in long-term care and support services.

**Recommendation 2:** Support planning and implementation of an applicable Medicaid waiver to build a continuum of home and community-based services, from crisis to long term supports, and increase access to brain injury and other neurocognitive services. Coverage for inpatient and residential neurobehavioral treatment should be considered for inclusion as part of this plan. This recommendation focuses on next steps for building out additional needed services identified by the 2022 DMAS Report on Planning for the Development of Services for Individuals with Brain

Injuries and Neurocognitive Disorders<sup>17</sup>, 2023 Brain Injury Services Steering Committee<sup>18</sup>, and 2023 Brain Injury Services Rate Study<sup>19</sup>, of which only Targeted Case Management for individuals with Traumatic Brain Injury was implemented in Virginia Medicaid in 2024.

**Recommendation 3:** Expand and build on successful DBHDS programs funded and implemented as the result of the 2021 Dementia Services Workgroup Report<sup>20</sup> and the 2022 DBHDS Report on State Hospital Discharge Process<sup>21</sup>. Current programs include Wytheville (Carrington Memory Care Partnership and Mt. Rogers Wythe House), Suffolk (Western Tidewater Dementia Programs), Waverly and Chilhowie (Nursing Home Partnerships), and Northern Virginia (RAFT Dementia Support Program). Please see the 2022 DBHDS Report on the Development of Programs for Individuals with Dementia Served by State Hospitals<sup>22</sup>, and the 2021-2022 DBHDS Quarterly Reports<sup>23</sup> on the Establishment of Census Pilot Projects on RGA LIS for more information.

- Explore options for developing evidence-based practices (EBPs) within existing programs and services for people with neurodevelopmental disabilities or neurocognitive disorders and co-occurring behavioral challenges (e.g., adapted cognitive behavioral therapy for individuals with neurodevelopmental disabilities). Ensure funding, including Medicaid rates, can support enhanced staffing to implement new EBPs.
- Strengthen administrative capacity needed to support regional coordination of state and local government partnerships with private providers to support individuals with neurocognitive disorders in integrated care models. Also, develop a plan to determine the best regional or otherwise targeted approaches that address service demand and availability and supports efficient use of state and local public resources to expand the capability and capacity of private providers to serve individuals with neurocognitive and neurodevelopmental disorders in the least restrictive setting possible. This comprehensive plan should also address funding (both startup and operational) and training needs, as discussed in other recommendations.

**Recommendation 4:** Utilize Pilot Private Hospital discharge funds to support individuals with neurocognitive disorders after an inpatient discharge. These pilot funds are intended to be used to support one-time costs, such as transportation and apartment setup <sup>24</sup>. Traditional discharge

https://rga.lis.virginia.gov/Published/2022/RD31/PDF.

https://rga.lis.virginia.gov/Published/2022/RD280/PDF.

<sup>&</sup>lt;sup>17</sup> DMAS. (2022). Report on Planning for the Development of Services for Individuals with Brain Injuries and Neurocognitive Disorders. https://rga.lis.virginia.gov/Published/2022/RD31/PDF.

<sup>&</sup>lt;sup>18</sup> DMAS. (2023). Brain Injury Services Steering Committee Report.

https://www.dmas.virginia.gov/media/5825/steering-commitee-deck-05-02-2023.pdf.

<sup>&</sup>lt;sup>19</sup> DMAS. (2023). Virginia Brain Injury Services Rate Study Final Presentation.

https://www.dmas.virginia.gov/media/6359/steering-committee-07-11-2023.pdf.

<sup>&</sup>lt;sup>20</sup> DBHDS. (2022). Report on the Development of Programs for Individuals with Dementia Served by State Hospitals. https://rga.lis.virginia.gov/Published/2021/RD801/PDF.

<sup>&</sup>lt;sup>21</sup> DBHDS. (2022). Report on the State Hospital Discharge Process.

<sup>&</sup>lt;sup>22</sup> DBHDS. (2022) Report on the Development of Programs for Individuals with Dementia Served by State Hospitals. https://dbhds.virginia.gov/about-dbhds/strategic-plans/.

<sup>&</sup>lt;sup>23</sup> DBHDS. (2022). Report on Item 320 CC.2 Report on the Establishment of Census Pilot Projects.

<sup>&</sup>lt;sup>24</sup> DBHDS. (2024). Report on Discharge Assistance Program (DAP).

https://rga.lis.virginia.gov/Published/2024/RD642/PDF.

assistance program (DAP) funds are primarily used to support the discharge of patients from state facilities and are allocated as such in the DBHDS grants to localities budget language. Item 296 P.2. of the FY 2025-FY 2026 budget authorized a pilot program to support the discharge of private hospital patients at risk of transfer to state mental health hospitals using a portion of allocated DAP funds. This budget language required DBHDS to prioritize assistance to patients who can be diverted from state hospital admission through discharge training, planning consultation, and/or one-time financial assistance. This recommendation would expand the current pilot to use these funds to assist with finding appropriate housing and support for individuals with neurocognitive disorders after discharge from inpatient hospitalization.

## Enhancements to Crisis Services

**Recommendation 5**: Identify the resources and training needed for supporting and expanding the capacity of REACH. Conduct a root cause analysis involving individuals, families, support coordinators, and other stakeholders. This analysis should aim to determine the challenges faced by individuals with neurodevelopmental disabilities in accessing supports and services and how to improve and standardize these services across the state including review and revise protocols for stakeholder roles and responsibilities for providing diversion services, as well as identify new models of care that can supplement or complement REACH. Please see the Crisis System page on the DOJ Settlement Agreement Library for more information on the current performance of the REACH program.<sup>25</sup>

**Recommendation 6:** Ensure that Crisis Receiving Centers (CRCs) and Residential Crisis Stabilization Units (RCSUs) build capacity and competency to support the needs of individuals with neurodevelopmental disabilities or neurocognitive disorders and behavioral health challenges (e.g., sensory rooms, designated space for caregivers to stay with the individual receiving services, protocols for funding and implementing increased staffing ratios when needed). Please see the Goal 6 of the DBHDS Strategic Plan Dashboard for more information on the current Virginia Crisis Connect build out.<sup>26</sup>

# Enhancements to Existing Community Inpatient Settings

**Recommendation 7:** Ensure an adequate number of private inpatient facilities in the Commonwealth that can support short-term admission of individuals with neurodevelopmental disabilities or neurocognitive disorders and behavioral challenges when inpatient care is clinically indicated. This includes identifying areas to support and addressing barriers such as opening specialty units, payment sources and rates to support increased staffing, guidance on when admission of individuals is permissible under licensing, creating sensory rooms, and identifying space for caregivers to stay with individuals receiving services.

**Recommendation 8:** Build capacity for providers to readmit individuals they had referred to crisis services after the crisis subsided. This includes supporting and building capacity among

<sup>&</sup>lt;sup>25</sup> Commonwealth of Virginia DOJ Settlement Agreement Document Library. https://dojsettlementagreement.virginia.gov/.

<sup>&</sup>lt;sup>26</sup> DBHDS Strategic Plan Dashboard. https://dbhds.virginia.gov/about-dbhds/strategic-plans/.

community providers through training programs and guidance to readmit individuals they had referred to crisis services after they have been stabilized through expansion of integrated behavioral health services. This recommendation would also include reviewing DBHDS, DSS, and VDH regulations to determine if changes can be made to encourage facilities to readmit individuals who were referred to crisis services once they have been stabilized.

**Recommendation 9:** Develop a plan to establish a best-in-class treatment and rehabilitation center in Virginia for individuals with neurodevelopmental disabilities, that includes a high intensity behavioral health services specialty care unit, outpatient, and crisis services. Such a center may also include community consultative services, workforce training, and caregiver education and support, through academic and other community partnership and collaboration. This recommendation is informed by the workgroup's review of neurobehavioral programs at the Kennedy Krieger Institute, a world class center for treatment of children with neurodevelopmental disabilities associated with Johns Hopkins University.

# **Communication and Information Sharing**

The workgroup recognized the critical need for effective communication among service providers supporting individuals throughout the continuum of care. Addressing communication barriers also enhances care coordination, enabling smoother transitions for individuals. This improved exchange of information will help prevent inappropriate placements or extended stays in state psychiatric facilities, ultimately leading to better outcomes for those receiving care. The following proposals were discussed to address this issue:

- Continue to support the expansion of the adoption of the emergency department care coordination (EDCC) system with the CSBs and state psychiatric hospitals as provided for in the EDCC plan and DBHDS IT plan.
- Individuals who have established services with a CSB should be ensured coordinated discharge planning to prevent re-admission to crisis and inpatient services. Private hospitals should be required to notify the individual's local CSB 24 hours prior to discharge from an inpatient setting, if the individual has already established services at the CSB or if the private hospital is referring the individual to the CSB to establish new services, to improve care coordination and transition between services.

**Recommendation 10**: Review and enhance requirements for policies and procedures for involvement of family/caregivers throughout the crisis response and intervention process. This should support participation during the ECO/TDO process, referral to alternative levels of care such as crisis services or other community-based services, and discharge planning from inpatient settings. Develop and distribute plain language educational materials to individuals and their supporters on how the crisis response and intervention process works and what their rights are during the process. This recommendation builds off the changes made by Otieno's Law passed during the 2024 legislative session.

**Recommendation 11**: Develop a best practice protocol that defines stakeholder roles and responsibilities for providing diversion services to individuals with neurocognitive disorders with behavioral challenges who present in the emergency department. In addition, DBHDS should

develop strategies to communicate efforts to improve REACH activities, capacity, capabilities, and coverage as referenced in Recommendation 4. Please see the Crisis System page on the DOJ Settlement Agreement Library for details on the performance of the REACH program.<sup>27</sup>

# **Build Workforce Capacity and Competency**

The workgroup discussed that the existing workforce lacked capacity and expertise to adequately support individuals with neurodevelopmental disabilities and neurocognitive disorders with behavioral health challenges and co-occurring conditions. Enhancing the capability of the existing workforce to care for these individuals will expand the availability of placements capable and willing to care for these individuals. The following proposals were discussed to address this issue:

# Training

**Recommendation 12**: Implement comprehensive training programs for staff at state facilities and work with Virginia Hospital and Healthcare Association (VHHA) to support private hospitals to develop and demonstrate competency in supporting individuals with neurodevelopmental disabilities and neurocognitive disorders. This training should equip healthcare professionals with the knowledge and skills necessary to provide effective, compassionate care tailored to the unique needs of these individuals. Consider further incentives such as enhanced payments for specialty training or certifications for professionals specializing in serving individuals with neurodevelopmental disabilities or neurocognitive disorders.

**Recommendation 13**: Create and implement a training curriculum for Mobile Crisis, Crisis Receiving Center (CRC), Residential Crisis Stabilization Unit (RCSU) providers, and 988 call center staff on serving patients with co-occurring neurodevelopmental disabilities and/or neurocognitive disorders with challenging behaviors.

**Recommendation 14**: Identify funding resources to support providers to offer training to direct care staff, including residential/institutional facilities and HCBS providers, on best practices for supporting individuals with neurodevelopmental disabilities or neurocognitive disorders and cooccurring behavioral health challenges across the continuum of care.

# **Support Caregivers**

The workgroup listened to numerous caregivers who shared their traumatic experiences due to challenges accessing needed services for individuals with neurodevelopmental disabilities and neurocognitive disorders facing behavioral health challenges. Caregivers play a vital role in helping these individuals remain in the least restrictive settings, advocating for their needs, and preventing unnecessary placements in state facilities. Providing caregivers with the support they

<sup>&</sup>lt;sup>27</sup> Commonwealth of Virginia DOJ Settlement Agreement Document Library. https://dojsettlementagreement.virginia.gov/.

need is essential for improving outcomes for both them and the individuals they care for. The following proposals were discussed to address this issue:

**Recommendation 15**: Identify appropriate funding mechanisms to support expanding access to respite care providers trained to support individuals with complex care needs.

**Recommendation 16**: Review and strengthen requirements for policies and procedures for ensuring that family members and caregivers are provided with multiple means for visitation (including in person, video, and telephonic) to ensure they are permitted appropriate access to communicate with individuals receiving care and support them in advocating for their needs across service settings. Identify and implement communication strategies to support stakeholder awareness of visitation rights. This recommendation builds from the changes made by Otieno's Law passed during the 2024 legislative session.

**Recommendation 17**: Identify and implement strategies to simplify the process for creating psychiatric advanced directives, develop infrastructure to support provider access to advanced directives, and educate stakeholders on how to create, access, and implement advanced directives. Psychiatric advance directives can be beneficial by providing clear instructions and preferences for care during a behavioral health crisis when caregivers are not immediately available. This tool can empower caregivers and dependent individuals by outlining treatment options and support preferences and ensuring that their voices are heard. Identify and implement strategies to support access to voluntary services for individuals with a psychiatric advance directive or with a consenting legal guardian or medical power of attorney.

# Acknowledgements

The Office of Secretary of Health and Human Resources extends appreciation and gratitude to the members of the Workgroup, as well as to the dedicated DBHDS' and DARS' staff. A special thank you to those who presented and shared their personal experiences with the Workgroup, which was critical to informing this report.

# Appendices

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

# Member Roster

Office of the Secretary of Health and Human Resources: Secretary Janet V. Kelly Office of the Secretary of Health and Human Resources: Deputy Secretary Leah Mills Senator Barbara Favola Delegate Vivian Watts Office of the Executive Secretary of the Supreme Court of Virginia: Jonathan Green Alzheimer's Association: Joshua Myers The Arc of Virginia: Tonya Milling The Arc of Virginia: Lucy Cantrell Behavioral Health Commission: Nathalie Molliet-Ribet Brain Injury Association of Virginia: Linda Wilkinson Decriminalize Developmental Disabilities: Brian Kelmar Department of Aging and Rehabilitative Services: Catherine Harrison Department of Behavioral Health and Developmental Services: Commissioner Nelson Smith Department of Behavioral Health and Developmental Services: Alexis Aplasca, MD Department of Behavioral Health and Developmental Services: Heather Norton Department of Medical Assistance Services: Angie Vardell disAbility Law Center of Virginia: Nicole Durose Family Member: Lyndsy Robinson Family Member: Yukiko Dove The Faison Center: Byron Wine Mental Health Virginia: Bruce Cruser Mount Rogers Community Services Board: Sandy Bryant *NAMI-VA*: Nick Macrini NeuroRestorative: Karin Addison Partnership for People with Disabilities: Teri Morgan Partnership for People with Disabilities: Seb Prohn Psychiatric Society of Virginia: Trevor Moncure Richmond Behavioral Health Authority: Autumn Richardson Virginia Alliance of Brain Injury Service Providers: Jason Young Virginia Association of Community Services Boards: Jennifer Faison Virginia Autism Project: Ann Flippin Virginia Board for People with Disabilities: Nia Harrison Virginia Association of Chiefs of Police: Dana Schrad

Virginia College of Emergency Physicians: Joran Sequeira, MD Virginia College of Emergency Physicians Aimee Perron-Seibert Virginia College of Emergency Physicians: Lauren Webb Virginia Health Care Association: Keith Hare Virginia Hospital and Health Care Association: Christine Schein Virginia Network of Private Providers: Jennifer Fidura Virginia Sheriffs' Association: Elizabeth Hobbs Vocal Virginia: Heather Orrock Western Tidewater Community Services Board: Deborah Dashiell



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### 21 OCT 2024

To: HB888/SB176 Work Group Organizers and Members

From: Jennifer Faison, Executive Director, VACSB

Re: Comments on Key Findings and Draft Recommendations from HB888/SB176 Work Group

The Virginia Association of Community Services Boards (VACSB) appreciates the opportunity to provide comments on the key findings and draft recommendations related to proposed changes in HB888/SB176.

### **Comments on Key Findings**

The VACSB agrees with the key findings developed during the work group meetings. The VACSB would like to emphasize:

- the notion that eliminating access to state psychiatric hospitals prior to the development of appropriate clinical options for individuals with neurocognitive and neurodevelopmental disorders does not address the underlying causes for individuals with these conditions being placed in state hospitals; and
- the fact that no amount of training could fully address the nuances involved in making a determination as to whether presenting behaviors during a crisis are caused by a neurocognitive or neurodevelopmental disorder or a mental illness, especially given the time in which an evaluation must be completed.

### **Comments on Recommendations**

Overall, the VACSB is comfortable with the draft recommendations with some additional comments for consideration:

- In order to realize any of these recommendations, the state will need to make significant investments in the system of care, over and above what has been invested in the past several years. While the VACSB supports not moving forward with a reenactment of the enabling legislation for this work group, the group should continue to meet to develop robust budget plans for the implementation of these recommendations.
- Many of the recommendations point to the need to develop services and supports that can divert individuals from state psychiatric hospital settings. This is the best option for all involved, but there will always be instances in which an individual has a neurocognitive or neurodevelopmental disability

VACSB Officers Chair: Patrick Sowers 1<sup>st</sup> Vice Chair: Gib Sloan, Chesterfield CSB 2<sup>nd</sup> Vice Chair: Ingrid Barber, Alleghany Highlands Community Services Secretary: Stephanie Clark, Alleghany Highlands Community Services Treasurer: Bernetta Watkins, Crossroads CSB Past Chair: Angelo Wider Executive Director: Jennifer Faison (with or without a mental illness) and is a danger to him or herself or to others and will need an appropriate setting to move through the crisis. Not only do we need options for diversion from inpatient care, we need appropriate settings for those instances when diversion is not possible.

- With regard to Recommendation 3 Ensure that that responsibility for monitoring the Discharge Assistance Program (DAP) plans for these individuals does not fall upon the CSB's unless there is funding available to support enhanced training and staffing. This more widely opens the door to private facilities accessing DAP, and if that is the long-term goal, there needs to be infrastructure established to support it.
- With regard to Recommendation 4 The state should also consider models that could supplement or complement REACH, recognizing that REACH programs are currently expected to fill gaps in the continuum of care that they are not able to fill.
- With regard to Recommendation 5 Some Crisis Receiving Centers (CRCs) have already come online and others are in the planning or early implementation stages. Requiring changes to physical infrastructure to accommodate additional components/requirements after the fact may be a challenge in some locations and will require additional funding to implement.
- With regard to Recommendation 9 Training for staff working in CRCs should include components to
  address how best blend populations of individuals with developmental disabilities and other
  individuals with mental illness who may have more externalizing behaviors. This can help avoid the
  harms of an overly stimulating environment. The implementation of this and other training needs to
  be appropriately funded.
- With Regard to Recommendation 15 This seems to be more of a statement of the value of advanced planning for individuals and families. This recommendation could be made more robust if it specifically addressed the need to streamline the process for putting an advance directive in place, create a statewide access point for the plans and implement marketing campaigns to ensure widespread knowledge of the importance of advance directives and how to access support to engage in said planning.

Thank you for considering these comments and the VACSB looks forward to continued participation on this group and any future iteration of it.

If you have any questions regarding the above comments, please contact Jennifer Faison at <u>ifaison@vacsb.org</u>, (804) 330-3141.

#### VACSB Officers Chair: Patrick Sowers 1<sup>st</sup> Vice Chair: Gib Sloan, Chesterfield CSB 2<sup>nd</sup> Vice Chair: Ingrid Barber, Alleghany Highlands Community Services Secretary: Stephanie Clark, Alleghany Highlands Community Services Treasurer: Bernetta Watkins, Crossroads CSB Past Chair: Angelo Wider Executive Director: Jennifer Faison





### HB 888/SB176 Recommendations

Submitted by Brain Injury Association of Virginia and the Virginia Alliance of Brain Injury Services Providers

#### **Enhancing-Expanding Services**

- Targeted home and community-based services for persons with brain injury that complement and does not duplicate, and more importantly does not threaten the existing network of brain injury service providers, already serving nearly 3,000 Virginians with brain injury, regardless of waiver eligibility.
  - We endorse focused services to include access to intensive neurobehavioral services and appropriate transitional/step down services as person returns to community settings
  - While we acknowledge the state hospital system is not an ideal placement for persons with brain injury, they remain a vital cog in the continuum of care until Virginia is able to fund and build out an appropriate neurobehavioral system of care. We recommend the expanded use of DAP funding to support appropriate transitional services to the community from state hospitals during this transition phase.
  - We strongly urge the development of an 1115 waiver to demonstrate the effectiveness of a waiver solely focused on providing residential supports to persons with brain injury. This would blunt the impact of the CMS conflict free case management rule and allow the creation of a system that worked collaboratively with critical safety net services already in place that have been proven effective. Forcing the current network of state funded brain injury programs into a 1915 HCBS brain injury waiver imperils the existence of this our state funded service system. Additionally, a 1115 waiver would provide a cost and time efficient approach to address our lack of appropriate neurobehavioral care throughout the Commonwealth.
- Creation of Permanent Supportive Housing (PSH) program and units for persons with brain injury

### **Communication and Training:**

- Create and implement training protocols for personnel involved during crisis intervention on working with persons with brain injury, including requiring all 988 crisis programs (Call Center staff, Mobile Crisis, Crisis Received Centers, Residential Crisis Stabilization Units) to having Qualified Brain Injury Service Provider (QBISP) and Certified Brain Injury Specialist (CBIS) certified providers on staff.
- Ensure brain injury module of CIT training is implemented in all police forces throughout Virginia
- Training of and collaboration with state funded brain injury services system on new 988/Marcus Alert systems being implemented throughout Virginia
- Develop training protocol for state hospital and private hospital staff for supporting persons with brain injury and for coordination with state funded service system prior to discharge to enhance smooth transition from hospital back to community

#### Family-Caregiver Supports:

- Expanding mental health supports, counseling services and resources for caregivers of persons with brain injury.
- Develop and implement training materials specific to caregivers for persons with brain injury.
- Expand access to respite care providers trained to support individuals with complex care needs.



# Achieve with us

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October 22, 2024

To Whom It May Concern:

Thank you for your work on the HB888/SB176 workgroup. At The Arc of Northern Virginia, a large part of what we do is help families navigate resources and challenging times through free workshops, print and digital materials, emails, calls, case management, and public guardianship. In our more than 60 years of operation, we have never before seen the dramatic rise in needs related to behavioral crises that we have in the last decade.

All too often we're contacted by a family whose loved one has been arrested, dumped from a residential placement with nowhere to go due to behavioral support needs, or people hearing about these challenges and worried that their loved one is next. It is terrifying, dangerous, and untenable. Virginia must act swiftly to develop a comprehensive and thoughtful crisis response and navigation system for the developmental disability (DD) community that keeps us all safe.

We have some thoughts and concerns from the proposed recommendations of the HB888/SB176 workgroup that we would like to share.

- 1. We know people with developmental disabilities, especially autism and even more so for people of color, are overrepresented in our criminal justice system. We need a screening tool before or at the time of police involvement to better identify and divert these individuals from a criminal justice system not designed to meet their needs.
- 2. Families are overwhelmed and terrified by the current Emergency Custody Order (ECO) and Temporary Detention Order (TDO) process. People often hear of them for the first time in the midst of a crisis and no written or other information is provided to the individuals under the order, families, or friends to help them understand what is going on, why, what rights have been removed, and what options remain for next steps. Plain language information should be provided to everyone involved in this process, along with training and resources to ensure these tools are not used in excess or to the detriment of the DD population.
- 3. People with DD are often told they do not fit anywhere in our current system. Mental health practitioners will deny them service or care, and they are told there are no options other than overcrowded and ill-fitting public mental health facilities. If this door is to be closed, it can only be done so after another, well-designed and full functioning DD-focused crisis support option is in place.

Any physical crisis response placement must be developed with input and expertise from the DD (and especially autism) community, and piloted to ensure it is meeting the unique needs of this population. Specialized staff support, training, and physical materials are needed for people with sole DD diagnosis, as well as those with co-occurring mental health needs. Training should include developing expertise on communication methods, including AAC, common in the DD community. Locations must be throughout the geographically diverse state, as we've seen too often that families cannot support individuals who are in crisis centers far away from the family/caregiver home.

4. There must be assurances that no one in crisis will be told they have to wait for a support option. By definition, they do not have time to do that if actively in a crisis.

- 5. We know our existing Waiver system, inclusive of the REACH model, is not working for people with ongoing and/or episodic behavioral support needs. Families reach out in tears, desperate to find someone who will come help, provide care immediately, and offer high-quality ongoing caregiving. REACH has not been successful in the last decade in stepping up to appropriately meet this need, and we have grave concerns about proceeding with this model as the sole solution to expanding crisis care to DD Waiver families.
- 6. There is undoubtedly a great deal of work to be done to make Virginia a safe place for those in crisis. We would like to see an ongoing workgroup that provides oversight, feedback, and guidance as we build any future crisis systems.
- 7. We strongly support these proposed recommendations:
  - a. Enhance the continuum of care by adding in more robust Waiver crisis care, while ensuring those on the DD Waiting list and those eligible who have not yet applied are also able to access crisis supports
  - b. Offering more resources and training to crisis response teams, with an eye on DD-expertise and training
  - c. Ensuring crisis centers do not lump together populations with wildly divergent needs
  - d. Having a public, in-patient option for individuals who need to de-escalate and get appropriate supports before returning to community-based care
  - e. Increasing care options and training for those providing care
  - f. Working closely with the Community Services Board to ensure coordinated planning and prevention of re-admission
  - g. Utilizing tools to ensure people are diverted from the emergency department and from police involvement for disability, crisis, and mental-health related needs
  - h. Enhancing requirements for involvement of families and caregivers in the ECO/TDO process
  - i. Offering more respite care to prevent crisis, and increasing options for family involvement in all phases of the process
  - j. Encourage the use and understanding of Psychiatric Advanced Directives for those with mental health needs

Again, thank you for your time and work on this thus far, and going forward. We hope deeply for a day when we can honestly tell families their loved one will be safe and supported during and after a crisis.

With Gratitude,

Bendnell

Lucy Beadnell Director of Advocacy The Arc of Northern Virginia Lucy.Beadnell@TheArcofNOVA.org

# Feedback from Brian Kelmar, President and Co-founder of Decriminalize Developmental disabilities and parent advocate



# HB888/SB176 DRAFT Key Findings and Recommendations

### **Key Findings**

• The proposed changes to the code definition of mental illness in HB888/SB176 do not address the underlying causes that lead individuals with neurocognitive and neurodevelopmental disorders, who display behavioral challenges, to be placed in state psychiatric facilities. Changing the definition would eliminate the only available service option, state psychiatric hospitals, for many individuals with neurocognitive or neurodevelopmental disorders who are experiencing a behavioral health crisis.

We strongly disagree with this. We are not addressing the underlying issue. TDO and ECO should not be used in autism cases even with comorbid diagnosis unless the mental illness is the driving factor and not the autism that is causing the breakdown. Using the mental hospitals for our autistic population escalates and further traumatizes the individual and the family. If this is not the correct legislation, then we need to come up with new legislation that identifies and implements the solution. This is just reverting to the existing process which we have shown has been ineffective and detrimental to the induvial in the long run.

• Data from Virginia's DD Waiver population indicated that almost 70% of individuals with ID/DD have a co-occurring behavioral health condition that requires specialized behavioral health treatment.

It seems they're using statistics on mental illness in autistic individuals to oversimplify the causes of trauma, which can be misleading. It's crucial to consider the full context and avoid attributing trauma solely to mental illness. Each autistic person's experience is unique, and meltdowns are often triggered by external factors rather than mental illness itself. The data also overlooks that many autistic individuals develop conditions like depression, anxiety, or PTSD due to difficulties in understanding and navigating the world around them. Individuals with neurodevelopmental disabilities and neurocognitive disorders with behavioral health challenges lack adequate access to long-term care and support services and crisis services with the training and expertise to support them remaining in their current placement. When in-patient care is needed, individuals in these populations generally lack access to services and clinicians with the specialization required to meet their needs.

Autistic individuals often experience crises due to specific triggers, such as sensory overload or challenging situations. These outbursts are usually a result of frustration, as they struggle to communicate while in a heightened state of fight or flight. In such moments, their ability to express themselves is severely compromised, leading to panic and further escalation.

# Enhance the Continuum of Care

The workgroup identified need for access to more services for individuals with neurodevelopmental disabilities and neurocognitive disorders experiencing behavioral challenges that would prevent or provide alternative treatment locations to state facilities, including specialized high-intensity behavioral health services for individuals needing a higher level of care, crisis services, and specialized services and supports in long-term care and support services.

What has been the measure of success for existing systems? Anecdotal evidence from parents of autistic individuals suggests that current programs are not only ineffective but often harmful and detrimental. We cannot continue rolling out more programs without a proven track record of success. The issue is undeniably difficult and complex, but that does not excuse inaction or reliance on flawed systems. This was made clear during the DOJ settlement, where the court emphasized that complexity is not a valid reason for failing to act. We need legislation that directly addresses the needs of autistic individuals, with a realistic timeline for implementing the best practices, rather than defaulting to programs that have consistently failed them.

### Long-term care and support services

**Recommendation 2:** Support planning and implementation of an applicable Medicaid waiver to build a continuum of home and community based services, from crisis to long term supports, and increase access to brain injury and other neurocognitive services. Coverage for inpatient and residential neurobehavioral treatment should be considered for inclusion as part of this plan. This recommendation focuses on next steps for building out additional needed services identified by the 2022 DMAS <u>Report</u> on Planning for the Development of Services for Individuals with Brain Injuries and Neurocognitive Disorders, 2023 Brain Injury Services <u>Steering Committee</u>, and 2023 Brain Injury Services <u>Rate Study</u>, of which only Targeted Case Management for individuals with Traumatic Brain Injury was implemented in Virginia Medicaid in 2024.

### What are the specifics and when is this proposed to be implemented by?

### Crisis

**Recommendation 4**: Identify the resource needs for supporting and expanding the capacity of REACH, including conducting a root cause analysis involving individuals, families, support coordinators, and other stakeholders. This analysis should aim to determine the challenges faced by individuals with neurodevelopmental disabilities in accessing supports and services, and how to improve and standardize these services across the state. Please see the Crisis System page on the DOJ Settlement Agreement Library for more information on the current performance of the REACH program.

The root cause analysis should examine what has and hasn't worked for the autism community, identifying key areas for change. A detailed plan should be published, including timelines and specific goals for implementation. To ensure continuous improvement, ongoing surveys should

be conducted to assess the effectiveness of any changes. Additionally, a comprehensive survey of the disability community should gauge customer satisfaction, recognizing that families often hesitate to file complaints due to a lack of faith in the system.

Since the DOJ settlement agreement, the **REACH** program has faced persistent challenges. This program needs to be managed with oversight by an independent committee that has enforcement authority to ensure compliance and accountability. There must be clear, measurable indicators of its effectiveness. The current metrics have failed to capture its shortcomings, as many families have stopped using REACH due to poor past experiences. It's crucial that future evaluations accurately reflect the program's impact and make necessary adjustments.

### High Intensity Behavioral Health Services

**Recommendation 6:** Develop a plan to establish a best-in-class treatment and rehabilitation center in Virginia for individuals with neurobehavioral disorders, that includes a high intensity behavioral health services specialty care unit, outpatient, and crisis services. Such a center may also include community consultative services, workforce training, and caregiver education and support, through academic and other community partnership and collaboration. This recommendation is informed by the workgroup's review of neurobehavioral programs at the Kennedy Kreiger Institute, a world class center for neurobehavioral disorders associated with Johns Hopkins University.

The Kennedy Krieger Institute's presentation was impressive, but their model focuses on children and young adults, leaving a gap in addressing the needs of autistic individuals who are out of high school. This model is not suitable for our adult population, and further research is required to identify best-in-class approaches for adults with autism. While the objective is valuable, it may require legislation mandating a thorough study, with a report detailing what a suitable model would look like, including costs and a clear timeline for inclusion in the budget. Without this, it remains a lofty goal without a concrete path forward.

**Recommendation 7:** Increase the number of private facilities in the Commonwealth that are able to admit individuals with neurodevelopmental disabilities or neurocognitive disorders and behavioral challenges who need inpatient care. This includes identifying areas to support and addressing barriers such as payment sources and rates, guidance on when admission of individuals is permissible under licensing, creating sensory rooms, and identifying space for caregivers to stay with individuals receiving services. This also includes supporting and building capacity among community providers to readmit individuals they had referred to crisis services after they have been stabilized.

This is a possible solution. Since we're still building capacity, identify who the private providers are, identify their capacity, invest in them to expand their facilities and capacity while the state is building a long-term solution.

# **Communication and Care Coordination**

The workgroup recognized the critical need for effective communication among service providers supporting individuals throughout the continuum of care. Addressing communication

barriers also enhances care coordination, enabling smoother transitions for individuals. This improved exchange of information will help prevent inappropriate placements or extended stays in state psychiatric facilities, ultimately leading to better outcomes for those receiving care. The following proposals were discussed to address this issue:

- Continue to support the expansion of the adoption of the emergency department care coordination (EDCC) system with the CSBs and state psychiatric hospitals as provided for in the EDCC plan and DBHDS IT plan.
- Individuals who have established services with a CSB should be ensured coordinated discharge planning to prevent re-admission to crisis and inpatient services. Private hospitals should be required to notify the individual's local CSB 24 hours prior to discharge from an inpatient setting, if the individual has already established services at the CSB or if the private hospital is referring the individual to the CSB to establish new services, to improve care coordination and transition between services.

Communication must extend beyond these recommendations. A secure database and a push notification system are needed to alert the appropriate departments and community supports when someone is in crisis—similar to an emergency alert system. Effective communication is crucial, but current support groups have limited coordination. This would require identifying best practices, along with determining the costs and developing a timeline for implementation.

Summary recommendations:

- 1. Introduce Legislation for Crisis De-escalation and Alternatives: Legislation is needed to establish effective de-escalation strategies at the scene, and to provide viable alternatives if the situation cannot be resolved there. Simply reverting to the current process is not a solution. Autistic individuals should be kept out of the TDO (Temporary Detention Order) and ECO (Emergency Custody Order) processes, as jail or mental hospitals often escalate crises and cause more harm. Comorbid conditions should only trigger a TDO/ECO if a trained medical professional evaluates and determines that mental illness is the primary cause.
- 2. Identify Trained Private Facilities: The state should compile a list of private facilities specifically trained to handle autistic individuals in crisis. These facilities should be the primary options if the mobile crisis team is unable to de-escalate the situation on-site. This list must be readily available to mobile crisis response teams. Orginazations like Qlife in Henrico
- 3. Shift Response to Mobile Crisis Teams, Not Law Enforcement: Crisis response should move away from law enforcement and be handled by mobile crisis response teams. The state should adopt a model similar to the CAHOOTS program in Oregon, which effectively handles behavioral health crises.
- 4. **Require Dual Evaluations for Autistic Individuals in Crisis:** When an autistic individual in crisis is taken to a medical facility, both a medical and psychiatric evaluation should be conducted by professionals trained in autism. Meltdowns could be triggered by uncommunicated medical issues, and addressing these triggers is crucial for proper care.
- 5. *Implement Interim Crisis Leadership Team:* While long-term solutions are being developed, an interim solution is needed. A senior crisis leadership team should be established, available to be contacted by mobile crisis teams, first responders, or family

members. This team will be on a 24/7 response(Team members could take turns on off hours and weekends similar to an on call Doctors rotate this responsibility) This team would quickly mobilize the appropriate resources, including community supports, criminal justice professionals to prevent jail time, and medical and mental health experts, to de-escalate the situation and find longer-term solutions. This model could follow Louisiana's approach, where developmental disabilities have a dedicated crisis response team.

6. Establish an Independent Oversight Board: An independent oversight board, consisting of parents, advocates, and medical and mental health professionals, should be created. This board would hold agencies accountable for their crisis responses and have the authority to enforce proper actions, ensuring agencies meet the needs of autistic individuals in crisis.

#### **Overall comments:**

The recommendations presented are well-intentioned but lack clear substance, timelines, and identification of necessary resources. They default to existing programs that have not demonstrated success through measurable objectives. These goals need to follow the "SMART" framework—specific, measurable, achievable, relevant, and time-bound. The costs involved must be identified as part of this review, with clear accountability, schedules, and measurable outcomes.

Additionally, there should be specific recommendations on where autistic individuals should go if they need to be removed from a location during a crisis. More concrete actions are needed to support autistic individuals in these recommendations. Critically, there is no plan addressing the reality that many autistic people are ending up in the criminal justice system. Families who call 911 or 988 should not fear that their request for help will result in costly legal fees, jail time, or even death. Legislation must be enacted to keep this vulnerable population from entering the criminal justice system during a crisis.

While the discussions have been thorough, the recommendations fall short of meeting the original objective: finding real solutions and identifying the resources required.

Recommendations listed in red are provided by

Brian Kelmar President & Cofounder Decriminalize Developmental Disabilities

b.kelmar@dthree.org



October 23, 2024

RE: Draft Key Findings and Recommendations of SB176/HB888 Workgroup

To Whom It May Concern:

Please see the comments below regarding the draft recommendations from the SB176/HB888 Workgroup. Thank you to everyone that participated and thank you for the opportunity given to the autism community to submit comments and input throughout this process.

As everyone agrees, the issue of inappropriate response and insufficient support for neurodevelopmental individuals in crisis is difficult and long standing.

### The Problem and the Question to be Answered

The current Virginia patchwork system of supports for people with disabilities (PWD) consists of large gaping holes where there is no support and is an instrument in itself of trauma for the individual in crisis and for their family or caregivers.

State mental health hospitals do NOT treat autism. They do not willingly admit autistics and if they are sent there by the jails, they turn them around and send them immediately back to jail. It is inappropriate to admit PWD to mental health hospitals and "[t]hese inappropriate admissions include individuals with neurocognitive disorders (i.e., dementia) and neurodevelopmental disorders (i.e., autism spectrum disorder), who accounted for 10 percent of state psychiatric hospital discharges in FY23. While they are a small percentage of state hospital patients, they stay for relatively long periods even though state hospital staff generally do not have the expertise to appropriately care for them."<sup>1</sup>

Private mental health hospitals also hold people against their will to maximize insurance payouts.<sup>2</sup>

It is unsafe and precarious for autistics to be held in jail or admitted to a mental health hospital. The Joint Legislative Audit and Review Commission (JLARC) in their 2022 review of Virginia's State Mental Health Hospitals said "state psychiatric hospital staff frequently reported concerns regarding the safety and well-being of patients with neurocognitive and neurodevelopmental diagnoses."<sup>3</sup>

<sup>&</sup>lt;sup>1</sup> <u>Summary: Virginia's State Psychiatric Hospitals, pg 2</u>.

<sup>&</sup>lt;sup>2</sup> How a Leading Chain of Psychiatric Hospitals Traps Patients

<sup>&</sup>lt;sup>3</sup> <u>Summary: Virginia's State Psychiatric Hospitals, pg 2</u>.



It is hazardous for autistics to encounter law enforcement. Common police tactics such as ramping up verbal instructions, moving closer or even making physical contact can quickly backfire and escalate an incident. By age 21, approximately 20% of youth with autism had been stopped and questioned by police and nearly 5% had been arrested. <sup>4</sup> Death at the hands of law enforcement in Virginia is not uncommon.<sup>56</sup>

Families are afraid to call for help if there is a behavioral crisis because of the known dangers to autistics from law enforcement, especially if they are black or brown families. Parents and caregivers manage a crisis at home as long as they can and only call when there is nothing else they can do.

Considering all of these concerns, SB176/HB888 specifically asked for meaningful recommendations to address what everyone recognizes as a disastrous failure of care for the neurodevelopmental population in a behavioral health crisis. Question to be answered: if we can't send neurodevelopmental or neurobehavioral individuals to jail or mental health hospitals, where do they go when they are in crisis?

The Workgroup recommendations were developed by staff at DBDHS but do not address this fundamental question in the enacting legislation.

- (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;<sup>7</sup>

### Why the current system is failing

"Individuals with neurodevelopmental disabilities and neurocognitive disorders with behavioral health challenges lack adequate access to long-term care and support services and crisis services with the training and expertise to support them remaining in their current

<sup>&</sup>lt;sup>4</sup> <u>Rava J, Shattuck P, Rast J, Roux A. The Prevalence and Correlates of Involvement in the Criminal Justice</u> System Among Youth on the Autism Spectrum. J Autism Dev Disord. 2017 Feb;47(2):340-346. doi: 10.1007/s10803-016-2958-3. PMID: 27844248.

<sup>&</sup>lt;sup>5</sup> https://www.cnn.com/us/live-news/irvo-otieno-death-virginia-video-release-03-21-23/index.html

<sup>&</sup>lt;sup>6</sup> When Police Encounters With Autistic People Turn Fatal

<sup>&</sup>lt;sup>7</sup> <u>SB176/HB888 2024 Virginia Legislative Session</u> .



placement. When in-patient care is needed, individuals in these populations generally lack access to services and clinicians with the specialization required to meet their needs."<sup>8</sup>

"Nearly all private inpatient facilities in the state have neurodevelopmental disability and neurocognitive disorder as an exclusionary criteria for admission. Because of this criteria, individuals with these conditions cannot receive care in private inpatient facilities notwithstanding a diagnosed co-occurring mental illness, further causing negative impact to the individual and caregiver seeking behavioral health support."<sup>9</sup>

In 2021, as a part of the Department of Justice (DOJ) Settlement Agreement, Virginia established a Crisis Office at the state level with a goal to "develop a community-based, traumainformed, recovery-oriented crisis system that will respond to a crisis where it is occurring rather than relying on the local emergency department or law enforcement as the primary way to access crisis care."<sup>10</sup> The purpose of this Crisis Office is to implement the Crisis Plan to comply with the requirements of the Settlement Agreement.

### 1. <u>Crisis Services</u>

- a. <u>The Commonwealth shall develop a statewide crisis system for individuals with</u> intellectual and developmental disabilities. The crisis system shall:
  - i. Provide timely and accessible support to individuals with intellectual and developmental disabilities who are experiencing crises, including crises due to behavioral or psychiatric issues, and to their families;
  - ii. Provide services focused on crisis prevention and proactive planning to avoid potential crises; and
  - iii. Provide in-home and community-based crisis services that are directed at resolving crises and preventing the removal of the individual from his or her current placement whenever practicable.
- b. <u>The crisis system shall include the following components:</u>
  - i. Crisis Point of Entry
    - A. The Commonwealth shall utilize existing CSB Emergency Services, including existing CSB hotlines, for individuals to access information about and referrals to local resources. Such hotlines shall be operated 24 hours per day, 7 days per week and staffed

<sup>&</sup>lt;sup>8</sup>Key Findings of Workgroup SB176/HB888 page 1.

<sup>&</sup>lt;sup>9</sup>Key Findings of Workgroup SB176/HB888 page 2.

<sup>&</sup>lt;sup>10</sup> DOJ Settlement, Crisis System



with clinical professionals who are able to assess crises by phone and assist the caller in identifying and connecting with local services. Where necessary, the crisis hotline will dispatch at least one mobile crisis team member who is adequately trained to address the crisis.

B. By June 30, 2012, the Commonwealth shall train CSB Emergency Services personnel in each Health Planning Region ("Region") on the new crisis response system it is establishing, how to make referrals, and the resources that are available.

### ii. Mobile crisis teams

- A. Mobile crisis team members adequately trained to address the crisis shall respond to individuals at their homes and in other community settings and offer timely assessment, services, support, and treatment to de-escalate crises without removing individuals from their current placement whenever possible.
- B. Mobile crisis teams shall assist with crisis planning and identifying strategies for preventing future crises and may also provide enhanced short-term capacity within an individual's home or other community setting.
- C. Mobile crisis team members adequately trained to address the crisis also shall work with law enforcement personnel to respond if an individual with ID/DD comes into contact with law enforcement.
- D. Mobile crisis teams shall be available 24 hours per day, 7 days per week and to respond on-site to crises.
- E. Mobile crisis teams shall provide local and timely in-home crisis support for up to 3 days, with the possibility of an additional period of up to 3 days upon review by the Regional Mobile Crisis Team Coordinator.
- F. By June 30, 2012, the Commonwealth shall have at least one mobile crisis team in each Region that shall respond to on-site crises within three hours.



- G. By June 30, 2013, the Commonwealth shall have at least two mobile crisis teams in each Region that shall respond to on-site crises within two hours.
- H. By June 30, 2014, the Commonwealth shall have a sufficient number of mobile crisis teams in each Region to respond on site to crises as follows: in urban areas, within one hour, and in rural areas, within two hours, as measured by the average annual response time.

### iii. <u>Crisis stabilization programs</u>

- A. Crisis stabilization programs offer a short-term alternative to institutionalization or hospitalization for individuals who need inpatient stabilization services.
- B. Crisis stabilization programs shall be used as a last resort. The State shall ensure that, prior to transferring an individual to a crisis stabilization program, the mobile crisis team, in collaboration with the provider, has first attempted to resolve the crisis to avoid an out-of-home placement and if that is not possible, has then attempted to locate another community based placement that could serve as a short-term placement.
- C. If an individual receives crisis stabilization services in a community-based placement instead of a crisis stabilization unit, the individual may be given the option of remaining in the placement if the provider is willing and has capacity to serve the individual and the provider can meet the needs of the individual as determined by the provider and the individual's case manager.
- D. Crisis stabilization programs shall have no more than six beds and lengths of stay shall not exceed 30 days.
- E. With the exception of the Pathways Program operated at Southwestern Virginia Training Center ("SWVTC"), crisis stabilization programs shall not be located on the grounds of the Training Centers or hospitals with inpatient psychiatric beds. By July 1, 2015, the Pathways Program at SWVTC will cease providing crisis stabilization services and shall be replaced by offsite crisis stabilization programs with sufficient capacity to meet the needs of the target population in that Region.



- F. By June 30, 2012, the Commonwealth shall develop one crisis stabilization program in each Region.
- G. By June 30, 2013, the Commonwealth shall develop an additional crisis stabilization program in each Region as determined necessary by the Commonwealth to meet the needs of the target population in that Region.

If this crisis services system was in place as required and as designed, then a large majority of these PWD in crisis would not be ending up in jail or mental health hospitals. The system that the state has put is place, Regional Education Assessment Crisis Habilitation Services (REACH) has not come anywhere close to fulfilling its 86% target. (That isn't even an "A" grade.) They are currently at 55% completion of REACH crisis assessments.<sup>11</sup>

The fact that families are experiencing arrests, contact with law enforcement and traumatic admissions to hospital Emergency Departments is proof positive that the crisis system Virginia has in place is failing miserably.

# The Key Findings and Recommendations of This Workgroup Do Not Address the Needs of the Autism Community in Crisis.

The Key Findings are numbered and comments are in italics.

- The proposed changes to the code definition of mental illness\_in HB888/SB176 do not address the underlying causes that lead individuals with neurocognitive and neurodevelopmental disorders, who display behavioral challenges, to be placed in state psychiatric facilities. <u>Changing the definition would eliminate the only available service option, state psychiatric hospitals, for many individuals with neurocognitive or neurodevelopmental disorders who are experiencing a behavioral health crisis.
  </u>
  - This sounds like you think you can put ASD in state psychiatric hospitals and that would be an answer. (See JLARC Report)
  - This finding completely ignores the JLARC Report that says: "<u>State hospitals also</u> <u>have seen an increase in inappropriate admissions.</u> If an individual has been determined to meet the criteria for a TDO, but does not actually have a condition that requires psychiatric treatment, statute still requires state hospitals to admit them, which is counterproductive for these individuals' treatment and unsafe for

<sup>&</sup>lt;sup>11</sup> https://dojsettlementagreement.virginia.gov/dojapplication/provision/iii.c.6.a/



them. <u>These inappropriate admissions include individuals with neurocognitive</u> disorders (i.e., dementia) and <u>neurodevelopmental disorders (i.e., autism</u> <u>spectrum disorder</u>), who accounted for 10 percent of state psychiatric hospital discharges in FY23. While they are a small percentage of state hospital patients, they stay for relatively long periods even though state hospital staff generally do not have the expertise to appropriately care for them. In addition, state psychiatric hospital staff frequently reported concerns regarding the safety and well-being of patients with neurocognitive and neurodevelopmental diagnoses. "(Emphasis added).

- Standard definitions of "mental health" likewise do not address the underlying causes of behavioral issues. Bipolar disorder, schizophrenia, etc (along with ASD) are <u>collections of observed symptoms</u> that may or (and most often) may not respond to standard treatments and are difficult to tease out with Autistics. For example, PANDAS is an autoimmune disorder that results from a strep infection that presents with behaviors that are often diagnosed as a mental health issue. Treating the underlying medical condition relieves the "mental health" presentation.
- Data from Virginia's DD Waiver population indicated that almost <u>70% of individuals with</u> <u>ID/DD have a co-occurring behavioral health condition that requires specialized behavioral</u> health treatment.
  - ASD co-morbidity statistics are likewise <u>flawed</u>.
  - ASD individuals' behavioral symptoms that match an existing diagnostic label without an understanding of the underlying cause(s). For example: PANDAS presents with OCD, Tics, anxiety, aggression but is an autoimmune disorder resulting from brain inflammation after an infection. How about long-term COVID?
- 3) Individuals with neurodevelopmental disabilities and neurocognitive disorders with behavioral health challenges lack adequate access to long-term care and support services and crisis services with the training and expertise to support them remaining in their current placement. When in-patient care is needed, individuals in these populations generally lack access to services and clinicians with the specialization required to meet their needs.
  - Agree
- 4) The current workforce does not have the necessary expertise to effectively support these individuals. By <u>strengthening the skills and capabilities of existing staff</u>, we can significantly increase the number of placements equipped to care for them at all levels of the care continuum.
  - Existing staff are trained to existing models of psychiatric care primarily psychotropic drugs coupled with cognitive behavior therapy. Changing longstanding current institutional approaches to treatment is an extremely difficult task that requires leadership, funding and extensive staff "buy-in".



- 5) Communication barriers, especially during a behavioral health crisis, can result in individuals with neurodevelopmental or neurocognitive disorders being inappropriately placed or kept longer than necessary in state facilities. <u>Providing adaptive communication support is essential to ensure they receive appropriate care and placement.</u>
  - Augmentative and Alternative Communication (AAC) devices are very much needed throughout the system. JLARC study indicates that current state facilities cannot meet this particular need of the autism population.
  - How will adaptive communication support redress the current systemic failures? Do not put AAC devices in the current state system and call that a completed task.
- 6) Caregivers play a critical role in supporting individuals in the least restrictive settings, advocating for their needs, and preventing unnecessary placements in state facilities. To continue fulfilling this vital role, caregivers and legal decision-makers must receive comprehensive information, resources, so they can effectively support the individual's behavioral health crisis. <u>Strengthening this support network is essential to ensuring the best outcomes for those they care for.</u>
  - What do you specifically envision would strengthen the caregiver support network that isn't already in place? If you have a proposal then make it a part of a pilot program to test its efficacy and show its outcomes.
- 7) Training certified prescreeners and magistrates alone cannot ensure the successful implementation of HB888/SB176. The clinical complexity of determining whether an individual's behavior stems from a neurodevelopmental disorder, a neurocognitive disorder, or a mental illness goes beyond what training can address—especially given the current qualifications required for prescreeners and the strict timeline for completing Temporary Detention Order (TDO) evaluations during the Emergency Custody Order (ECO) period. Additionally, without immediate access to appropriate services that meet the unique needs of this population, no amount of training will fill this critical gap.
  - Access to appropriate services is indeed the key to solving NC/ND behavioral treatment crisis. The prescreeners cannot be screeners that are employed by the provider facilities. (*See Acadia NYT article*)<sup>12</sup>
  - Training of magistrates and court personnel along with law enforcement and sheriffs is an important piece and can be coordinated with prescreeners that are certified, have access to medical records and are remote via telehealth call. If autism is found or even suspected, then they must be diverted.

<sup>&</sup>lt;sup>12</sup> How A Leading Chain of Psychiatric Hospitals Traps Patients

https://www.nytimes.com/2024/09/01/business/acadia-psychiatric-patients-trapped.html



• Placing ECO/TDO timelines requirement above appropriate placement is indeed placing "the cart before the horse". Common multi-day waits in ER routinely fail to meet those "strict timelines" without penalty other than what is suffered by the autistic individuals and their caregivers. Again a systemic failure that this Workgroup fails to address.

#### Legislative Recommendations

**Recommendation 1**: The workgroup commends the patrons of HB 888/SB 176 for introducing legislation which seeks to address the inappropriate placement of individuals with neurocognitive and neurodevelopmental disabilities in state hospitals. The workgroup agrees that placement in a state hospital is not appropriate for people with neurocognitive disorders or neurodevelopmental disabilities who are experiencing a behavioral health crisis that arises from their neurocognitive disorder or neurobehavioral disability and not from mental illness. The workgroup recognizes that a spectrum of care, including more community placements are needed for these individuals. However, at this time for individuals with neurocognitive or neurodevelopmental disabilities who are experiencing a behavioral health crisis there are few options outside of state psychiatric hospital placement. If the door to state psychiatric facilities is closed to individuals with neurocognitive or neurodevelopmental disabilities there may be no other options for individuals in crisis and their families. State hospital placement is their last option. Therefore, the workgroup recommends that HB888/SB176 not be reenacted as currently written. The recommendations contained in this report are steps towards improving existing services and developing new services which could help divert individuals from state psychiatric hospital placement. Until these types of services better cover Virginia, the workgroup finds reenacting this legislation would likely not have the desired effect for several reasons:

• Private inpatient facilities could be mandated by law to eliminate those exclusionary criteria. The real question is "where can "appropriate services" for the autistic population can be accessed?" Current answer is neither state nor private facilities can provide, so don't leave this current system in place.

Changing the statutory definition of mental illness would require certified prescreeners and magistrates to determine whether an individual's behaviors are the sole manifestation of a neurodevelopmental or neurocognitive disorder during the ECO and TDO process.

- Determination of "sole manifestation" criteria is a practical impossibility. However, determination of appropriate services for ASD individuals is the critical question. If Autism is diagnosed or suspected, then the assumption must be to screen for separate services.
- It may be possible to make this determination with confidence for some individuals when their medical and psychiatric history is known and their behaviors appear to be consistent with their neurodevelopmental or neurocognitive diagnosis.

TDO evaluations must occur within the eight-hour ECO period. The purpose of the TDO evaluation is to determine if an individual meets Virginia's code requirements for involuntary civil commitment, not to conduct a comprehensive behavioral health diagnostic assessment. Further, <u>prescreeners are not required to be licensed clinicians</u> and cannot make complex diagnostic decisions during a crisis evaluation.



• Recommend that pre-screeners of course be licensed clinicians.

Many individuals who are evaluated are not previously known to the CSB prescreener evaluating them, and medical and psychiatric information is not accessible at the time of evaluation. Even if that history is accessible, <u>individuals with underlying neurodevelopmental and neurocognitive</u> <u>disorders may not have a formal diagnosis.</u>

• Recommend that prescreeners err on the side of caution – if caregivers or interviewees give credible evidence of autism then screen for Neurodevelopmental Disorder and divert.

Some individuals with neurodevelopmental and neurocognitive disorders with behavioral challenges may have co-occuring mental illnesses that have not been formally diagnosed. It may not be possible to determine whether their behaviors are a sole-manifestation of these disorders during the ECO period. Making this determination is complex and time intensive and requires comparing their behaviors to their unique baseline.

- Is this an excuse to submit ASD individuals to <u>inappropriate</u> treatment?
- Does this give the system the right to traumatize the individual in the name of too much time and too complex? System currently provides for inappropriate detention/treatment. The system is traumatizing the individuals.
- The Workgroup response is (Shrug) basically to continue the status quo.
- If ASD is suspected by any indication- the family, the individual, support professionals- then ASD should be diverted to another appropriate placement.

**Recommendation 2:** Support planning and implementation of an applicable Medicaid waiver to build a continuum of home and community based services, from crisis to long term supports, and increase access to brain injury and other neurocognitive services. Coverage for inpatient and residential neurobehavioral treatment should be considered for inclusion as part of this plan. This recommendation focuses on next steps for building out additional needed services identified by the 2022 DMAS Report on Planning for the Development of Services for Individuals with Brain Injuries and Neurocognitive Disorders, 2023 Brain Injury Services Steering Committee, and 2023 Brain Injury Services Rate Study, of which only Targeted Case Management for individuals with Traumatic Brain Injury was implemented in Virginia Medicaid in 2024. Recommendation 3: Expand and build on successful DBHDS programs funded and implemented as the result of the 2021 Dementia Services Workgroup and Report and the 2022 DBHDS Report on State Hospital Discharge Process. Current programs include Wytheville (Carrington Memory Care Partnership and Mt. Rogers Wythe House), Suffolk (Western Tidewater Dementia Programs), Waverly and Chilhowie (Nursing Home Partnerships), and Northern Virginia (RAFT Dementia Support Program). Please see the 2022 DBHDS Report on the Development of Programs for Individuals with Dementia Served by State Hospitals, and the 2021-2022 DBHDS Quarterly Reports on the Establishment of Census Pilot Projects on RGA LIS for more information. To support expansion of these pilots, the workgroup identified the following potential actions:

**Recommendation 4**: Identify the resource needs for supporting and expanding the capacity of REACH, including conducting a root cause analysis involving individuals, families, support coordinators, and other stakeholders. This analysis should aim to determine the challenges faced



by individuals with neurodevelopmental disabilities in accessing supports and services, and how to improve and standardize these services across the state. Please see the Crisis System page on the DOJ Settlement Agreement Library for more information on the current performance of the REACH program.

**Recommendation 5:** Ensure that Crisis Receiving Centers (CRCs) and Residential Crisis Stabilization Units (RCSUs) build capacity and competency to support the needs of individuals with neurodevelopmental disabilities or neurocognitive disorders and behavioral health challenges (e.g., sensory rooms, designated space for caregivers to stay with the individual receiving services, protocols for funding and implementing increased staffing ratios when needed). Please see the Goal 6 of the DBHDS Strategic Plan <u>Dashboard</u> for more information on the current Virginia Crisis Connect build out.

- *REACH, by its own data and by every comment received by families who have used REACH services, is a disaster that has not lived up to it promised effectiveness even when given a goal post that is less than satisfactory (86%). The fact we are here today addressing these systemic failures is in a large part due to the ineffectiveness of the REACH program.*
- We all understand that DBDHS has placed all its eggs in one basket however, cut your losses and develop a program that actually achieves the goals you set for it to comply with your Settlement Agreement with the DOJ.

**Recommendation 6:** Develop a plan to establish a best-in-class treatment and rehabilitation center in Virginia for individuals with neurobehavioral disorders, that includes a high intensity behavioral health services specialty care unit, outpatient, and crisis services. Such a center may also include community consultative services, workforce training, and caregiver education and support, through academic and other community partnership and collaboration. This recommendation is informed by the workgroup's review of neurobehavioral programs at the Kennedy Kreiger Institute, a world class center for neurobehavioral disorders associated with Johns Hopkins University.

• Kennedy Kreiger Institute (KKI) is **not** a model that takes adults, works with the court system, is a prompt response to an individual in a crisis nor is it part of an ECO/TDO process. This is the only resource like this that presented to the Workgroup. Do research and find a program that provides a continuum of care for juveniles and adults. Implement a pilot program and prove its efficacy for the problems presented.

**Recommendation 7:** Increase the number of private facilities in the Commonwealth that are able to admit individuals with neurodevelopmental disabilities or neurocognitive disorders and behavioral challenges who need inpatient care. This includes identifying areas to support and addressing barriers such as payment sources and rates, guidance on when admission of individuals is permissible under licensing, creating sensory rooms, and identifying space for caregivers to stay with individuals receiving services. This also includes supporting and building capacity among community providers to readmit individuals they had referred to crisis services after they have been stabilized.



- *A complete pilot study (including appropriate involvement of private facilities)* <u>before expanding either public or private capacity.</u>
- Establish independent oversight and guardrails to ensure this does not become another place to dump and board individuals for long periods of time.

**Recommendation 8**: Identify funding resources to support providers to offer training to direct care staff, including residential/institutional facilities and HCBS providers, on best practices for supporting individuals with neurodevelopmental disabilities or neurocognitive disorders and cooccurring behavioral health challenges across the continuum of care.

- Complete pilot program to determine actual best practices for end-to-end evaluation/screening/treatment/discharge/follow-on which all require effective communication between systems.
- Lack of communication in this patchwork system Virginia uses was acknowledged by everyone as a systemwide shortcoming. Effective communication between systems is crucial for someone in crisis needing help.

**Recommendation 9**: Create and implement a training curriculum for Mobile Crisis, Crisis Receiving Center (CRC), Residential Crisis Stabilization Unit (RCSU) providers, and 988 call center staff on serving patients with co-occurring neurodevelopmental disabilities and/or neurocognitive disorders with challenging behaviors.

- Complete pilot program to determine actual best practices for end-to-end evaluation/screening/treatment/discharge/follow-on which all require effective communication between systems.
- Lack of communication in this patchwork system Virginia uses was acknowledged by everyone as a systemwide shortcoming. Effective communication between systems is crucial for someone in crisis needing help.

**Recommendation 10**: Implement comprehensive training programs for staff at state and private hospitals to develop and demonstrate competency in supporting individuals with neurodevelopmental and neurocognitive challenges. This training should equip healthcare professionals with the knowledge and skills necessary to provide effective, compassionate care tailored to the unique needs of these individuals. Consider further incentives such as enhanced payments for specialty training or certifications for professionals specializing in serving individuals with neurodevelopmental disabilities or neurocognitive disorders.

• Complete pilot program to determine actual best practices for end-to-end evaluation/screening/treatment/discharge/follow-on which all require effective communication between systems.



• Lack of communication in this patchwork system Virginia uses was acknowledged by everyone as a systemwide shortcoming. Effective communication between systems is crucial for someone in crisis needing help.

**Recommendation 11**: Develop a best practice protocol that defines stakeholder roles and responsibilities for providing diversion services to individuals with neurocognitive disorders with behavioral challenges who present in the emergency department. Review DBHDS, DSS, and VDH regulations to determine if changes can be made to encourage facilities to readmit individuals who were referred to crisis services once they have been stabilized. Review and revise protocols for stakeholder roles and responsibilities for providing diversion services for individuals with neurodevelopmental disabilities through REACH. In addition, DBHDS should develop strategies to communicate efforts to improve REACH activities, capacity, capabilities, and coverage. Please see the Crisis System page on the DOJ Settlement Agreement Library for more information on the current performance of the REACH program.

**Recommendation 12**: Review and enhance requirements for policies and procedures for involvement of family/caregivers throughout the crisis response and intervention, including during an ECO/TDO, referral to alternative levels of care such as crisis services or other community-based services, and planning for discharge from inpatient settings. This recommendation builds off the changes made by Otieno's Law passed during the 2024 legislative session.

- The whole point of this Workgroup was to develop a placement and plan for diverting someone with ID/DD/ASD out of the ECO/TDO process. We are not sure how many ways we can continue to say... <u>it is your process that is causing the trauma and damage to individuals and their caregivers in crisis</u>. Divert neurodevelopmental and neurobehavioral individuals from the process you developed to handle neurotypical populations and individuals in mental health crisis.
- Once someone is inside an ECO/TDO process then everything is out of their hands and the system has to play out. No family input is respected nor will it be under your tepid recommendations.

**Recommendation 13**: Expanding access to respite care providers trained to support individuals with complex care needs and provisions for streamlining access to increased staffing ratios when they are needed. This includes the identification of funding mechanisms to support these services.

**Recommendation 14:** Ensure that family and caregiver is provided with multiple means for visitation (including in person, video, and telephonic) to ensure they are permitted appropriate access to communicate with individuals receiving care and support them in advocating for their needs across service settings. This recommendation builds from the changes made by Otieno's Law passed during the 2024 legislative session.



**Recommendation 15:** A psychiatric advance directive can be particularly beneficial, as it provides clear instructions and preferences for care during a behavioral health crisis when caregivers are not immediately available. This tool can empower caregivers and dependent individuals by outlining treatment options and support preferences, ensuring that their voices are heard. Additionally, it is important to recognize that there are often more voluntary options available than temporary detention orders for individuals in crisis, which can help facilitate more appropriate care.

#### **Recommendations by Families and Caregivers**

The Virginia Autism Project submitted draft recommendations and goals from the autism community that aligned with the structure that the Workgroup had created in September 2024. Please see that document.

Additionally we reiterate:

- 1. Use a Sequential Intercept Model (SIM) to examine how individuals with an autism spectrum disorder come into contact with and move through the criminal justice system. Do not try to solve this monumental problem with a "consensus" of people in the room after 30 days of presentations and minimal discussion.
- 2. Design appropriate settings and resources across the Commonwealth with a continuum of services and smooth handoffs to next step in the process. Do NOT keep the current patchwork of services with gaps.
- 3. Put any proposal in place in a pilot program and test its outcomes. Run all the scenarios presented by families through this system and see if it solves the problems they experienced.
- 4. This requires Virginia to create specialized settings that include: calming surroundings, trained staff, opportunity for respite, therapy services, and opportunity for medical care. Do not integrate with populations that mimic the jails and mental health hospitals where they are currently inappropriately sent. When they are in crisis, autistics cannot manage themselves in those settings and it will create more trauma and stress to this vulnerable population. It is a violation of their Human Rights to continue this approach.
- 5. <u>Independent oversight for review and accountability of the system.</u> Make sure the system is actually working rather than as you currently do with REACH and just hope it will all work out when it clearly is not meeting the needs of ASD in crisis.
- 6. Keep individuals OUT of the justice system and at the minimum provide training for Magistrates, Judges, Court Clerks, Sheriff Departments, Commonwealth Attorney Offices, Emergency Call Centers and of course Law Enforcement/ Emergency Medical teams.
- 7. Integrate technology so that all of the pieces of the system (prescreeners, law enforcement, 988, 911, CSB, hospitals, courts, etc.) can communicate in real time even 24 hours a day to help someone in crisis.
- 8. Return individuals to family and community without seizing them and boarding them indefinitely.



- 9. Listen to law enforcement representatives who say this situation is untenable and law enforcement does not belong at these events and want others to take responsibility for responding. (*See presentation by Dana Schrad 10.11.2024*)<sup>13</sup> Divert neurodevelopmental and neurobehavioral individuals who are in crisis and keep them safe from unintendedly injuring a law enforcement officer which results in devastating felony charges.
- 10. We also align with and support the comments by other advocacy groups concerning inputs for these Recommendations.

Respectfully submitted,

eresa L. 0.10

**Teresa L. Champion** Virginia Autism Project tchampion@virginiaautismproject.org

<sup>&</sup>lt;sup>13</sup> https://youtu.be/fu0pul-E7jw?feature=shared









Date: September 12, 2024

- To: The Honorable Leah Mills, Deputy Secretary of Health
- From: The Virginia College of Emergency Physicians, the Virginia Hospital & Healthcare Association, and the Psychiatric Society of Virginia/Washington Psychiatric Society
- Re: Draft Recommendations for Alternatives to HB888/SB176

Sent electronically (<u>LEAH.MILLS@GOVERNOR.VIRGINIA.GOV</u>)

The Virginia College of Emergency Physicians, the Virginia Hospital & Healthcare Association, and the Psychiatric Society of Virginia/Washington Psychiatric Society are writing today to first thank you, the Department of Behavioral Health and Developmental Services, and our fellow task force members for the time and attention this critical issue is receiving. We all agree that it is extremely important that Virginians with neurocognitive disorders and neurodevelopmental disabilities receive the care and support they need, especially if they are experiencing a mental health crisis.

We acknowledge there is much work still to be done in the Commonwealth to improve our mental health system and ensure individuals with neurocognitive disorders and neurodevelopmental disabilities are receiving appropriate services and in the most appropriate setting for their care needs. As such, we encourage continuation of the task force for an additional year to continue to find solutions and alternative placements to best serve the needs of these individuals.

While we commend the underlying goal of the HB888 and SB176—to ensure individuals receive the best care in the right setting—we cannot support the 2024 introduced versions of HB888/SB176 because we do not believe that taking away the safety net of the state psychiatric hospitals achieves this goal, especially before any alternative treatment settings are in place.

To that end, we respectfully request the following recommendations be considered for inclusion in the report to the General Assembly:

- 1. Collect data about where the greatest needs are in the state for alternative treatment options so we can direct pilot programs and monetary resources to those areas with the individuals in the highest need first.
- 2. Improve communication between providers for patients, both in the field, such as mobile crisis teams, as well as in the emergency department so community service boards (CSBs) and both private and public in-patient psychiatric facilities are making each other aware that the patient is in a crisis. One way to do so is to expand the adoption of the emergency department care coordination system with the CSBs and state psychiatric hospitals.

- 3. Offer grant funds to providers to open specialty units for individuals with either neurocognitive disorders or neurodevelopmental disabilities.
- 4. Provide funding for state psychiatric hospitals to create specialty programs to effectively manage care for individuals during a mental health crisis.
- 5. Better utilize and expand on VMAP training and help lines to assist providers on best practices when working with these individuals with a particular focus on medication management.
- 6. Provide resources and support for nursing homes and assisted living facilities to better support patients in long term care settings.
- 7. Increase the training for mobile crisis teams and mental health professionals embedded in police departments about the special needs of these individuals and create more such teams across the state.
- 8. Increase respite care for families and paid caregivers to keep the patients in the settings in which they are safest and most comfortable.
- 9. Identify best practices emerging from the regional partnerships between nursing homes and CSBs in Chilhowie and Waverly and secure necessary funding to expand similar services in additional regions or service areas where there is the highest need.
- 10. Provide discharge assistance funds to private hospitals to assist with finding appropriate housing and support for individuals after discharge from hospital.

Thank you again for the opportunity to participate in the task force.

#### SB176/HB888 Workgroup on Placements in Virginia for People with Neurocognitive Disorders and Neurodevelopmental Disabilities Secretary of Health and Human Resources

Draft Minutes - Meeting One

July 18, 2024, 2 PM to 4 PM

Patrick Henry Building, West Reading Room

In-Person Attendance: The Honorable Janet Kelly, Secretary of Health and Human Resources Leah Mills, Deputy Secretary of Health and Human Resources Nelson Smith, Commissioner of DBHDS Angie Vardell, DMAS Dr. Adam Kaul, Psychiatric Society of Virginia Nathalie Moliet-Ribet, Behavioral Health Commission Trevor Moore, Commonwealth Strategy on Behalf of PSV Aimee Peron Seibert, Commonwealth Strategy on Behalf of VACEP Jonathan Green, Office of the Executive Secretary Mark Smallacombe, Virginia Hospital and Health Care Association Catherine Harrison, Department of Aging and Rehabilitative Services Dr. Alexis Aplasca, Office of the Secretary of Health and Human Resources/DBHDS Elizabeth Hobbs, Virginia Sheriffs' Association Josh Myers, Alzheimer's Association of Virginia Karin Addison, Brain Injury Association Jennifer Faison, VACSB Heather Norton, DBHDS Judy Hackler, Virginia Assisted Living Association Nia Harrison, Virginia Board for People with Disabilities Virtual Attendance: April Payne, Virginia Health Care Association Autumn Richardson, Richmond Behavioral Health Authority Bruce Cruser, Mental Health Virginia Katherine Coffey-Vega, MD, Carillion Debbie Dashiell. NAMI Virginia Grayson Lewis, Office of Senator Favola Humaira Siddiqi, MD, Advocatee Jennifer Fidura, Virginia Network of Private Providers Joran Sequeira, Virginia College of Emergency Providers Lucy Cantrell, The Arc of Virginia Amanda Mueller, DBHDS Angie Orange, DBHDS Heather Orrock, VOCAL

Badr Ratnakaran, Carillion Sandy Bryant, Mt. Rogers CSB Christine Schein, Virginia Hospital and Health Care Association Seb Prohn, Partnership for People with Disabilities Teresa Champion, Advocate Brian Unwin, Carilion Yukiko Dove, Advocate

Welcome and Introductions – HHR Secretary Janet V. Kelly

Secretary Janet Kelly welcomed workgroup members, thanked Del. Watts and Sen. Favola for championing the needs of these populations, and discussed the importance of the recommendations the workgroup would develop.

Overview of SB176/HB888 workgroup charge, reenactment language, and Joint Legislative Audit and Review Commission (JLARC) report

Dr. Alexis Aplasca, Senior Clinical Advisor for Behavioral Health Transformation, Office of the Secretary, Health and Human Resources, and Deputy Commissioner for Clinical and Quality Management, DBHDS

Dr. Alexis Aplasca reviewed the workgroup direction from the enacting legislation and gave an overview of the origins of the workgroup in the 2023 Joint Legislative Audit and Review Commission Report. She reviewed the DSM-5 definitions of neurodevelopmental and neurocognitive disorders highlighting how these populations are distinct from one another and are broad diagnostic groupings that include individuals with a wide range of abilities and support needs. She referenced a 2023 study on Co-occurring mental illness and behavioral support needs in adults with intellectual and developmental disabilities in Virginia which shows that this population has increased rates of mental illness diagnoses than the general population.

#### **Current Processes and Programs**

• Review current Temporary Detention Order (TDO) and Involuntary Admission process Curt Gleeson, Assistant Commissioner, Division of Crisis Services, DBHDS

Curt Gleeson reviewed the current criteria in code for temporary detention orders and civil commitments. He gave an overview of how these code requirements are operationalized by certified prescreeners. He reflected on the strengths of this process in protecting individual's civil liberties as well as common challenges encountered by stakeholders.

• Programs currently operated by DBHDS and CSBs to support individuals with neurodevelopmental disabilities and neurocognitive experiencing behavioral health challenges Heather Norton, Acting Deputy Commissioner, Community Services, DBHDS Suzanne Mayo, Assistant Commissioner, Division of Facilities Services, DBHDS

Heather Norton provided additional remarks on the 2023 study on co-occurring mental illness and behavioral support needs for individuals with intellectual and developmental disabilities. Ms. Norton also provided a general overview on the Department of Justice Settlement Agreemetn compliance indicators as they relate to the work group topic.

Suzanne Mayo presented on the various state-supported and community-based behavioral health services for individuals with dementia.

Breakout Discussions and Report Back to Workgroup

Workgroup members and attendees discussed the questions presented to the group in advance. Attendees online also participated.

#### Next Steps/Adjourn

Work group members and participants discussed topics for discussion and presentation at future meetings.

The meeting was adjourned at 4:10 PM.

#### 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."

#### **Discussion Questions**

- 1. How do the treatment needs of individuals with primary diagnoses of neurocognitive disorders and neurodevelopmental disabilities differ?
- 2. What are the top three most significant barriers and needs in Virginia's system of care for people with neurocognitive disorders and neurodevelopmental disabilities?
- 3. What supports (e.g. regulatory changes, licensing changes, etc.) do existing congregate care residential settings (residential treatment, group homes, sponsor homes, family homes, assisted living facilities, nursing homes) need that they don't currently have to admit and successfully support individuals with neurocognitive disorders when they exhibit challenging behaviors?
- 4. Same question as above but for individuals with neurodevelopmental disabilities?
- 5. What programs and services have you heard about or experienced in Virginia that have been effective or successful that you would like to see have greater access or be expanded? What about in other states?



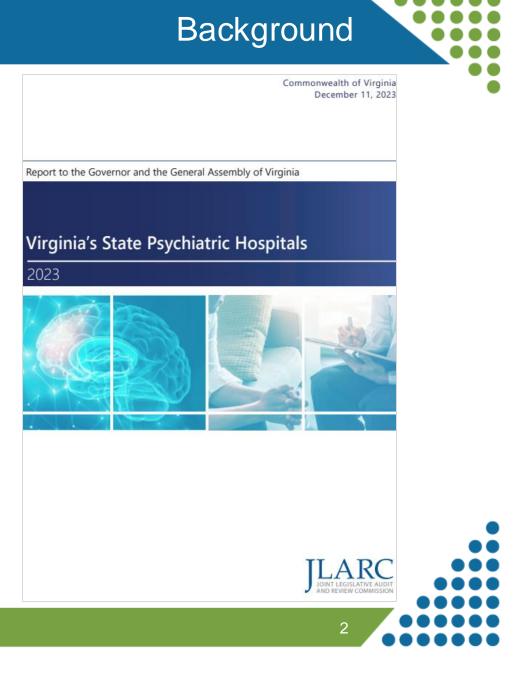


Workgroup on Placements for People with Neurocognitive Disorders and Neurodevelopmental Disabilities HB888/SB176 (2024)

Secretary of Health and Human Resources



- The Joint Legislative Audit and Review Commission (JLARC) reported on Virginia's State Psychiatric Hospitals in 2023
- Found individuals with a primary diagnosis of neurocognitive disorders and neurodevelopmental disabilities accounted for 10% of state psychiatric hospital discharges in FY 2023
  - Some had co-occurring mental health diagnoses
- These individuals had longer lengths of stay, staff reported they lacked expertise to care for these patients, and were at higher risk of victimization
- JLARC Recommendations 1-4 are based on these findings and inform SB176/HB888

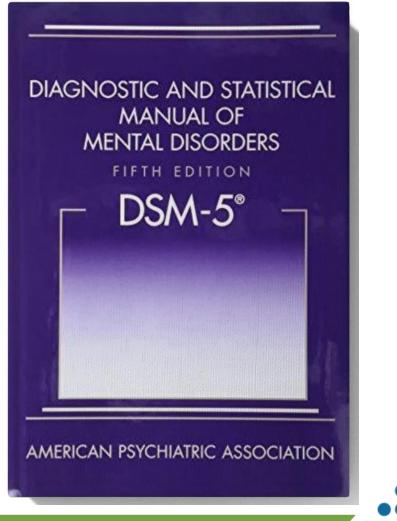






#### Neurodevelopmental Disorders

- A group of conditions with onset in the developmental period, often before a child enters grade school
- Characterized by developmental deficits that produce impairments of personal, social, academic, or occupational functioning
- The DSM-5 includes:
  - Intellectual Disability
  - Autism Spectrum Disorder
  - Global Developmental Delay
  - Communication disorders: language disorder, speech sound disorder, social (pragmatic) communication disorder, and childhood-onset fluency disorder (stuttering)
  - Attention Deficit-Hyperactivity Disorder (ADHD)
  - Specific Learning Disorders
  - Neurodevelopmental motor disorders: developmental coordination disorder, stereotypic movement disorder, and tic disorders
- In Virginia, 40% (females)/60% (males) of individuals with a developmental disorder (DD) have a mental health condition and/or behavioral support needs and approximately 50% of all individuals with DD are on at least 1 psychiatric medication for a mental health condition (<u>PPWD, 2023</u>)



**Presentation Title** 

#### Neurocognitive Disorders

- Characterized by decline from a previously attained level of cognitive functioning
- Delirium
  - An acute change in mental status due to an underlying medical condition
  - Reversible by treating the medical cause
    - Common causes: substance intoxication or withdrawal, medication side effects, infection, surgery, pain, or even simple conditions such as constipation or urinary retention
  - Can be life threatening if untreated
- Mild & Major Neurocognitive Disorder
  - Various causes ie Alzheimer disease, cerebrovascular disease, Lewy body disease, frontotemporal degeneration, traumatic brain injury, infections, and alcohol abuse
  - Mild memory impairment, decline in the ability to perform everyday activities, though still able to perform these activities without assistance, and difficulties with language, perceptual-motor and social skills – more than age related changes
  - Major Dementia
- Mood disturbances, including sudden increases in depression, bipolar-like mood swings or disinhibition, agitation, anxiety, or a sudden onset of apathy or dysthymia are often early indicators of the cognitive decline



DIAGNOSTIC AND STATISTICAL

MANUAL OF

MENTAL DISORDERS

FIFTH EDITION

DSM-5°

Definitions





#### HB888/SB176 Summary

1. Specifies that for the purpose of civil commitments and TDOs, behaviors and symptoms that manifest from a neurocognitive disorder or neurodevelopmental disability are excluded from the definition of mental illness and are, therefore, not a basis for placing an individual under a TDO or committing an individual involuntarily to an inpatient psychiatric hospital.

Provides that if a state facility has reason to believe that an individual's behaviors or symptoms are solely a manifestation of a neurocognitive disorder or neurodevelopmental disability, the state facility may require that a licensed psychiatrist or other licensed mental health professional reevaluate the individual's eligibility for a TDO before the individual is admitted and shall promptly authorize the release of an individual held under a TDO if the licensed psychiatrist or other licensed mental health professional determines the individual's behaviors or symptoms are solely a manifestation of a neurocognitive disorder or neurodevelopmental disability.

3. The provisions of the first enactment of this act shall not become effective unless reenacted by the 2025 Session of the General Assembly.





- 1. Evaluate the current availability of placements for individuals with neurocognitive disorders and neurodevelopmental disabilities who would otherwise be placed in state psychiatric hospitals;
- 2. 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;
- 3. Specify any additional funding or statutory changes needed to prevent inappropriate placements of such individuals in state psychiatric hospitals;
- 4. Provide recommendations for training of magistrates and CSBs related to the implementation of this act.





- 2021 DBHDS Dementia Services Workgroup and Report
- 2022 DBHDS Report on the Development of Programs for Individuals with Dementia Served by State Hospitals
- 2021-2022 Quarterly Reports on the Establishment of Census Pilot Projects
- 2022 DMAS Planning for the Development of Services for Individuals with Brain Injuries and Neuro-cognitive Disorders Workgroup and Report
- DOJ Settlement Agreement DBHDS Quarterly REACH Adult Data Summary Report, REACH Children Data Summary Report, Supplemental Crisis Report, Behavioral Supports Report; FY 2023 REACH Annual Report







#### Temporary Detention Order (TDO) and Involuntary Admission Process and Programs Supporting People with Neurodevelopmental Disabilities and Neurocognitive Disorders Experiencing Behavioral Health Challenges

HB888/SB176 Workgroup July 18, 2024







## **Goals for this Presentation**

- Review current involuntary commitment process
- Review programs currently operated and/or funded by DBHDS to support individuals with neurodevelopmental and neurocognitive disabilities experiencing behavioral health challenges







## **Current Involuntary Commitment Process**

Presented by: Curt Gleeson, Assistant Commissioner, Division of Crisis Services

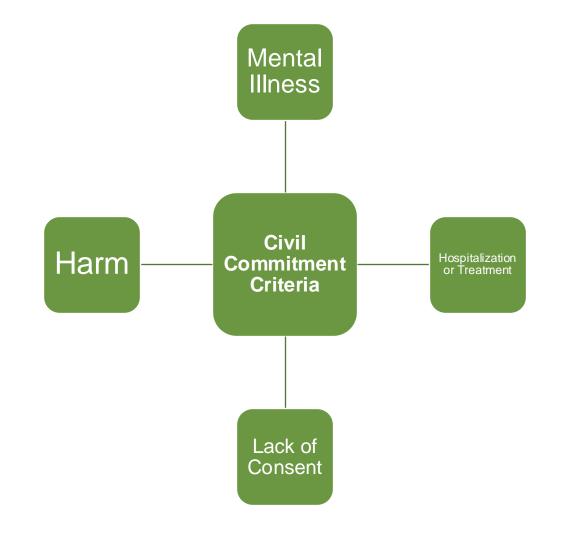






"the person (i) has a mental illness and that there exists a substantial likelihood that, as a result of mental illness, the person will, in the near future, (a) cause serious physical harm to himself or others as evidenced by recent behavior causing, attempting, or threatening harm and other relevant information, if any, or (b) suffer serious harm due to his lack of capacity to protect himself from harm or to provide for his basic human needs; (ii) is in need of hospitalization or treatment; and (iii) is unwilling to volunteer or incapable of volunteering for hospitalization or treatment." – VA Code §37.2-808(A) & § 37.2-809(B)

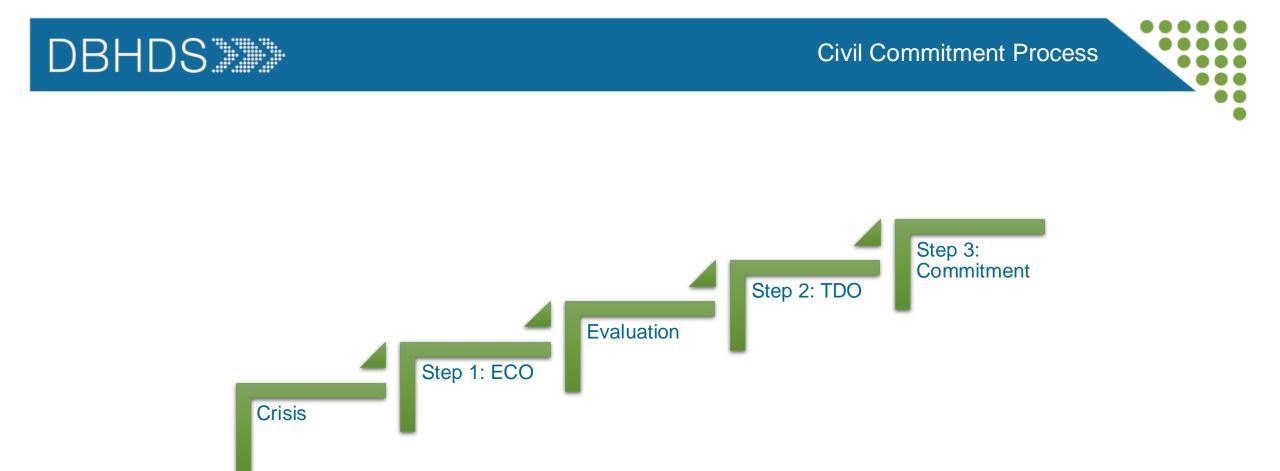






- Is the person battling a mental illness?
- Is the person at imminent risk of harm due to the mental illness?
- Is hospitalization or treatment the only way to mitigate the current risk that is due to the mental illness?
- Is the person unwilling or unable to volunteer for the hospitalization or treatment that is needed to mitigate the risk that is due to the mental illness?







Certified evaluator must assess to determine if statutory criteria is met. Only exceptions are:

- Previous evaluation within the last 72-hours
- "Significant physical, psychological, or medical risk to the person or to the persons associated with conducting such evaluation"

In order to petition magistrate for a TDO, the evaluator must identify:

- Criteria is met
- Willing facility to provide treatment

If the magistrate hears probable cause that statutory criteria is met, they will issue the TDO for further treatment and evaluation, naming the identified facility.







## Behavioral Health Services for Individuals with Developmental Disabilities

Presented by: Heather Norton, Acting Deputy Commissioner of Community Based Services







# Department of Justice

III.C.6.a.i – iii

The Commonwealth shall develop a statewide crisis system for individuals with intellectual and developmental disabilities. The crisis system shall:

i. Provide timely and accessible support to individuals with intellectual and developmental disabilities who are experiencing crises, including crises due to behavioral or psychiatric issues, and to their families;

ii. Provide services focused on crisis prevention and proactive planning to avoid potential crises; and

iii. Provide in-home and community-based crisis services that are directed at resolving crises and preventing the removal of the individual from his or her current placement whenever practicable.







## **Compliance Indicators**

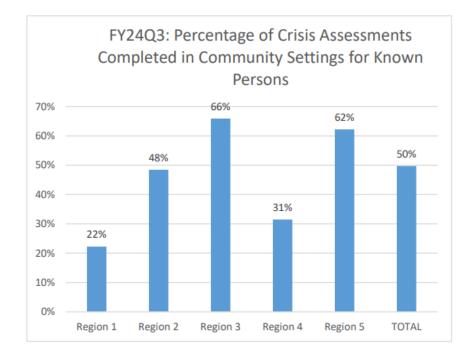
- Prevention
  - 22 indicators
  - Crisis Assessments in the Community
  - Behavioral Services
  - DSP availability
  - Psych hospital Admissions/Discharges
- Mobile Crisis
  - 7 indicators
- Crisis Stabilization
  - 7 indicators
  - CTH availability
  - Out of Home Prevention
  - Residential Services

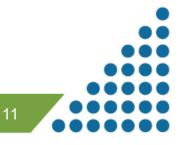






## Crisis Assessment in Community

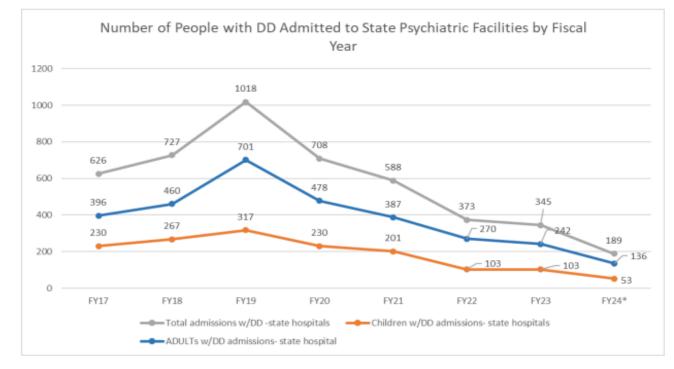








## State Psychiatric Hospitalizations



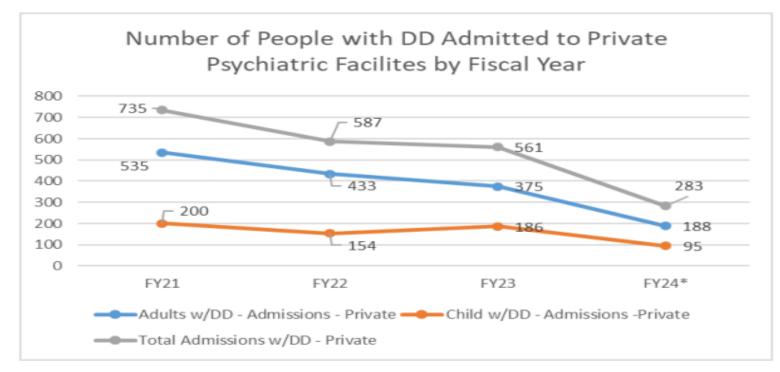
FY24 - Q1 and Q2 data only







## **Private Hospitalizations**



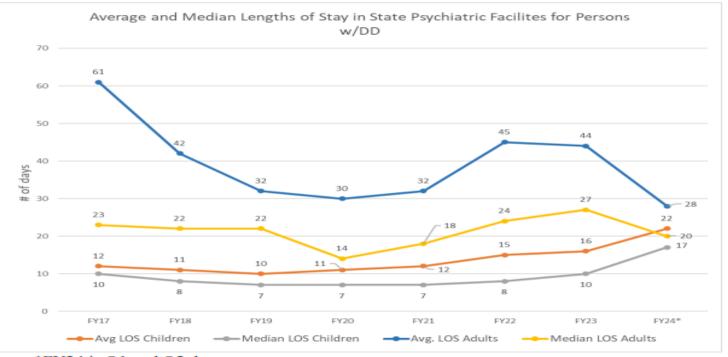
\*FY24Q1 - Q3 data only







## Length of Stay



#### \*FY24 is Q1 and Q2 data.







## Next Steps

- 3 new children CTHs
- Link Policy Academy
  - Administration for Community Living
  - NASMHPD
  - NASDDDS
  - NASHIA
  - NADD
- Best Practice in DD Mental Health Care
  - Cognitive Behavioral Therapy
  - "People with I/DD experience behavioral and physical health issues at rates higher than the general population and can benefit from the same evidence-based interventions which are used for people without I/DD. This series will feature specific interventions and treatments highlighting modifications and adaptations for people with I/DD. Our first set of videos focuses on Cognitive Behavioral Therapy Adaptations for people with I/DD. These sessions will explore adaptations to CBT which can benefit those with I/DD"
- Washington State
  - The Guidebook: Meeting the mental health needs of people with intellectual disabilities
  - Best practices for co-occuring conditions







## Behavioral Health Services for Individuals with Dementia

Presented by: Suzanne Mayo, Assistant Commissioner, Division of Facilities Services







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### 2021 Dementia Services Workgroup

- In 2021, there was a legislatively mandated workgroup that studied the needs and currently available resources for individuals with dementia who exhibit challenging behaviors.
- The workgroup found that there was a dearth of resources available for this population and for caregivers of this population. At that time, DBHDS began developing some resources for this population, including partnerships with Memory Care facilities and nursing homes, a caregiver community support program, and a crisis residential program.
- However, due to limited financial resources, these programs have only been able to serve a small proportion of the individuals with dementia who are referred for admission to state hospitals.
- <u>https://rga.lis.virginia.gov/Published/2021/RD801/PDF</u>





### Community-based dementia programs

- Carrington Memory Care Partnership (Wytheville)
- Western Tidewater Dementia Programs (Suffolk)
- Nursing Home Partnerships (Waverly and Chilhowie)
- RAFT Dementia Support Program (Northern Virginia)
- Mount Rogers Wythe House (Wytheville)







### Carrington Memory Care Partnership

- Started in 2023
- Partnership between Carrington Place in Wytheville, DBHDS, and Mount Rogers CSB
- Started with 20 beds, and recently expanded to 28
- Typically serves individuals discharging from state hospitals with neurocognitive disorders and other associated behaviors that require specialty memory and behavioral health care
- · Has served a total of 27 individuals, two of which were re-hospitalized
- Cost is around \$1 million annually.
  - This includes costs for Memory Care, beyond the Auxiliary Grant
  - Also covers costs for specialized behavioral health support staff from the CSB who work within the facility





### Tidewater Cove dementia care

- Started in FY23
- Partnership between Western Tidewater CSB and DBHDS
- Includes an interdisciplinary geriatric behavioral support team that supports individual in the facility and community
- Part of the larger Tidewater Cove assisted living facility, it includes 10 beds to provide memory care services
  - These beds can serve as respite beds, or for more permanent care
- Typically serves individuals discharging from state hospitals with neurocognitive disorders and other associated behaviors that require specialty memory and behavioral health care
- No individuals have been re-hospitalized; however, one individual was incarcerated for assaulting other residents and staff
- Cost is around \$1.2 million annually.
  - This includes costs for the Memory Care beds, beyond the Auxiliary Grant







### Nursing Home Partnerships

- Started in FY22
- Partnerships between nursing homes and CSBs (Waverly Nursing Home and Western Tidewater CSB; and Valley Nursing Home and Mount Rogers CSB)
- CSBs support the nursing homes to take individuals with more challenging behavioral needs by providing behavioral specialists and enhanced activities staff in the facility, frequent training for nursing home staff, and care coordination between the referring entity and the nursing home
- Also provided some funding for renovations/alternations to the facilities
- Programs serve individuals discharging from or diverting from a state facility, and are not limited to individuals with neurocognitive disorders (although these individuals make up about 50% of the individuals served by these partnerships)
- Re-hospitalization rates are less than 3%
- Cost is a little over \$1 million for both programs





### RAFT Dementia Support Program

- Started in FY23
- Partnership between Arlington CSB and DBHDS
- The RAFT program has been in existence for many years; however, this program was an expansion to focus on individuals with dementia
- Program focuses on support for caregivers, assisting individuals in staying in their homes, education, consultation, and respite care.
  - Also has partnered with a local university to assist in developing a pipeline for individuals to go into the field of geriatric/dementia care
- Over the past two years, has served 115 individuals and their families
- Cost is around \$750,000 annually.
  - This includes the cost for the team, and three respite beds at local assisted living facilities







### Wythe House

- Started in FY23
- It is a crisis stabilization-like facility for individuals with dementia who are in a behavioral and/or housing crisis
- 10 beds
- Provides specialized dementia care, including pharmacological and non-pharmacological interventions
- · Has served a total of 46 individuals
- Some individuals have long lengths of stay, due to the need for stabilization and to find permanent housing/supports
- Cost of the program is \$1.3 million annually, which includes the costs of staff, maintaining the home, etc.





### Challenges

- Procedural challenges with completing diversion activities during the ECO/TDO time period
  - Information exchange
  - Access to transportation
- Inconsistent identification of staff lead for supporting diversion
- Programs are voluntary; require consent by the individual or surrogate decision maker
  - If an individual does not have capacity and there is no surrogate decision maker identified they are not eligible for admission
  - Surrogate decisionmakers may not agree to diversion
- Programs do not have the capacity to support individuals with frequent combativeness/aggression
- Individuals may get "stuck" if placements cannot be identified for discharge







### Successes

- Multiple diversions and discharges from state hospitals
- Programs provide specialized dementia care that is unable to be provided in state hospitals
- All programs have also provided dementia care training within their communities
- Programs typically stay full
- Less expensive than state hospitalization
- Low re-hospitalization rates
- Positive feedback from state hospitals, CSBs, individuals, and family members





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#### 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 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 Deborah Dashiell, Western Tidewater Community Services Board



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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 both short-term crisis stabilization and long-term care for individuals with neurodevelopmental disabilities and neurocognitive disorders experiencing significant behavioral challenges. She highlighted the time limitation of the ECO process, which does not permit a more comprehensive evaluation, that the immediate focus of the TDO evaluation safety of the individual or others, and that pre-screeners are not trained to determine complex diagnoses. She noted that differentiating between crises caused by ND/NC disabilities and mental health conditions is crucial for appropriate intervention, and she encouraged the workgroup, when making a recommendation on the reenactment of the legislation, to consider the extent to which pre-screeners have the capacity to accurately determine the cause of a behavioral health crisis. Finally, she reminded the workgroup that recommendations should embody the guiding principles of choice, dignity, and least restrictive environment.

#### 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): to "free our patients/clients/students 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 that can effectively and safely manage challenging behavior, increase independence and quality of life, and maximize learning, especially for younger children. KKI prioritizes support for parents and guardians and their right to choice in the services provided to their children. Collaboration occurs across all clinical



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programs and external entities to support assessment of individuals' needs and inform service planning (e.g., state agencies, schools, insurance companies).

Dr. Hagopian emphasized that challenging behavior in individuals with neurodevelopmental disabilities is heterogeneous in etiology, presentation, and needs. Challenges change over time and require 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 each individual's unique requirements. He also highlighted the importance of distinguishing between management of challenging behavior and the treatment of challenging behavior. Ideally, as treatment progresses the need for management will be reduced or eliminated.

KKI uses the neurobehavioral model of care across all programs recognizing multiple determinants of behavior. Neurobehavioral programs at the institute include consultation with hospitals and schools, outpatient, intensive outpatient, and inpatient treatment. Multiple factors are considered when determining the level of service including severity of challenging behavior (impact on functioning, injuries), resistance to treatment, current and past services tried, services available locally, medical and nursing care needs, care giver goals and priorities, current placement, insurance coverage, and staffing resources. Dr. Hagopian shared a series of case examples demonstrating the successful treatment of individuals with challenging behaviors using the "neurobehavioral model of care".

The Neurobehavioral continuum of care provided by KKI is designed to match treatment levels with the severity of needs.

- The outpatient program is the largest and most commonly used, providing treatment for behavioral concerns with sessions of 2 hours per week over 3-4 months.
- The intensive outpatient program offers an intermediate level of care with 5 hours per day over 3 weeks, intensifying treatment.
- The inpatient program addresses the most severe cases, involving behavioral therapy and medical intervention for up to 5 months.

Several factors guide the selection of the appropriate care level, including primary clinical variables such as resistance to treatment, severity of behavior, past and current treatment, and available options. Additionally, considerations include caregivers' goals, the suitability of



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placement for achieving those goals, insurance coverage, staffing needs, and prior services used. The continuum of services is structured as follows:

- Outpatient: For moderate severity cases, where the individual is safe to transport, and few services have been provided previously.
- 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.
- 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.

The approach to treatment within the Neurobehavioral Programs involves Applied Behavioral Analysis (ABA), which can be integrated with other disciplines through co-treatment and consultation.

The Neurobehavioral model of care integrates several key components to address challenging behaviors effectively. It considers biological variables, such as the role of medication and behavioral treatments, in managing and modifying behavior. It also takes into account an individual's behavioral history, which provides insight into past patterns and responses. Additionally, the model evaluates the current environment to understand how external factors might influence behavior. Together, these elements help in creating a comprehensive and individualized approach to care.

Dr. Hagopian reviewed resources required for more severe and treatment-resistant challenging behavior. Resources included a dedicated interdisciplinary team and model of care, specialized facilities, protective equipment for staff and patients, systems for monitoring injuries and taking swift preventative action, well-described behavior management procedures to prevent injuries to staff from aggression and patient injuries related to self-injury, elopement, pica, and aggression. Dr. Hagopian noted that methods to train staff and ensure competency include didactic instruction and competency assessments (written), demonstration of skills (physical demonstration of competency), annual competencies to ensure skills are maintained, and ongoing feedback and coaching.

Dr. Hagopian concluded that providing personalized treatment for challenging behavior requires that we recognize the heterogeneity of challenging behavior in people with neurodevelopmental



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disabilities and match the level of service to the individual's need. To be successful, behavior interventions should be individualized based on the function of behavior and the individual's skills and preferences, and caregivers should be trained to high levels of proficiency.

**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 lived experience as a sibling and guardian of her adult brother who has Autism and experiences significant behavioral challenges. Her brother has experienced multiple behavioral health crisis and psychiatric hospitalizations. She highlighted challenges her family has experienced 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 in her role at Autism Society of Virginia. The family told her that the emergency room could not stabilize their loved one during a crisis, and private hospitals were unwilling to admit him due to his Autism. They were told that, if he was committed, he would have to go to a state facility and there are no alternative placements available for discharge. Ms. Flippin said that family outreaches like this one are increasingly frequent. 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 suggested that the workgroup prioritize listening to families, care givers, 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 safe 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

Ms. 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



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and symptoms can stem from a variety of diagnoses but that, during a crisis, the cause of behaviors or symptoms is not always known or readily distinguishable. She cautioned that without access to appropriate crisis and long-term care placements individuals with these conditions can end up stuck for long periods of time in emergency departments and hospitals, become involved in the criminal justice system, or homeless.

Ms. Harrison noted that individuals with neurocognitive disorders have a wide spectrum of symptom complexity. She shared that the majority can and are being served successfully in existing standard Home and Community Based Settings (HCBS) and Long-Term Care Settings (LTCS). 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 Long Term Care Services that are not permitted, offered, reimbursed/covered, or safe for other residents and staff in standard HCBS or LTC settings.

She reviewed common barriers individuals faced to receiving long term care services. Barriers included certain behaviors such as aggressiveness, active substance use, lack of family support, and criminal records. Some individual's income is too high and/or assets are too extensive to qualify for Medicaid long term care but are also too low to cover the costs privately. Additionally, some 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 reviewed their limitations emphasizing that none are designed to serve as Crisis Services or sustainable Long-Term Care Services, all had limited funding and services are not guaranteed, and all had access delays including 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, however, 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



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services and long-term intensive placements. She also stated that the system must evolve by investing in comprehensive training and increasing staffing levels.

#### **Stakeholder Perspectives:**

Jason Young – Community Brain Injury Services

Jason and his colleagues presented a case management summary an active case of a veteran experiencing homelessness with PTSD, brain injury, substance use disorder, and multiple cooccurring 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 resulting in arrest and multiple felony charges. He had no criminal history aside from minor traffic violations prior to his arrest. He is now at a state hospital for competency restoration.

The case managers emphasized that there was a significant lack of communication with community support team while the individual was receiving inpatient care at both private and public psychiatric facilities and their discharge plans were incoherent. They noted that the individual's arrest was the result of behavior associated with his suicide attempt and highlighted the systemic issue of arresting individuals experiencing behavioral health crisis. The team suggested that the workgroup consider amending code to require all inpatient psychiatric facilities to communicate with community case management teams.

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



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

Karen shared her lived experience speaking as a spouse to an individual with early onset Alzheimer's. Karen's husband experienced a behavioral health crisis while receiving respite care from family. During that time, his condition worsened, and he was taken by law enforcement to a hospital and placed in a psychiatric hold for a week. He experienced permanent regression significant loss of quality of life after that episode of treatment before his death a year later.

Karen recommended that the workgroup emphasize in their report that dementia patients and people with other neurocognitive and neurodevelopmental disabilities cannot all be treated the same. Each population has distinct needs that must be addressed differently 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 Irvo's law passed last session may address some of the problems Karen highlighted 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 began by highlighting that the population is aging rapidly, and our healthcare system is not equipped to support the increased demand for long-term care needs. Judy emphasized that there is a need to develop a continuum of long-term care housing support alternatives to hospitals noting that memory care can be included in both assisted living and nursing homes. She noted that when compared to nursing homes, assisted living has significantly more licensed providers and resident capacity with a lower average provider size. Assisted living is also less expensive than home health aides and nursing homes. Judy reviewed current funding sources for assisted living emphasizing that the number of assisted living facilities accepting the auxiliary grant (SSI



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

Supplement) has decreased steadily declining by almost half in the last 25 years. Virginia had an Alzheimer's Waiver Assisted Living Waiver that terminated in 2018. Judy noted that CMS has approved Medicaid Waivers with assisted living as a Home & Community Based setting highlighting 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 these capacity limitations.

Judy recommended that the workgroup review funding and support programs to make sure assisted living is included as a setting option, change payment allocations for Auxiliary Grant to be a true supplement instead of a subtraction 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 goals workgroup should be to develop effective interventions that support individuals and families and to prevent them 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 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 neurocognitive disorders. He highlighted a significant shortage of specialists in this field and lack of resources. 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 the reenactment of the legislation would remove a safety net without identifying alternative safe placements 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.

The Neurobehavioral Programs at Kennedy Krieger Institute: Optimizing Care for Individuals with Neurodevelopmental Disorders and Challenging Behavior

Louis Hagopian, Ph.D.

Program Director, Neurobehavioral Programs





### Individuals Served in the Neurobehavioral Programs

- Children and adults with neurodevelopmental disabilities with challenging behavior or other behavioral dysfunction
  - Challenging Behaviors: Aggression, self-injurious behavior (SIB), destructive behavior, pica, elopement
  - Avoidance, noncompliance with essential activities, skills deficits
  - Contributing medical, neurological, psychiatric problems

# Fundamentally,

Our aim is to free our patients/clients/students and their families from the burdens of challenging behavior so they can live their lives

### Challenging Behavior in Individuals with Neurodevelopmental Disabilities

- Heterogeneous in etiology, presentation, and needs
  - And individual's challenges change over time
  - So we must have a range of services to meet these needs
  - And we must personalize interventions for each individual
- Assessment and treatment requires specialized resources
  - Clinical expertise
  - Staffing, staff training
  - Policies and procedures to ensure safety and quality
  - Specialized facilities

# Our Values

- The safety and welfare of the person served is the highest priority
- Parents/guardians should be supported, and have a right to choose
- Persons served have a right to:
  - Make choices to the fullest extent of their abilities
  - The least restrictive intervention necessary that can:
    - Effectively and safely manage challenging behavior;
    - Increase independence and quality of life; and
    - Maximize learning

• These values drive our mission of service, research, training, advocacy

# Optimizing Care: Matching the Service to the Needs of the Individual

Matching the Treatment to the Individual Patient

The Neurobehavioral Continuum of Services

### The Neurobehavioral Programs

# **Consultation** with Hospitals/Schools

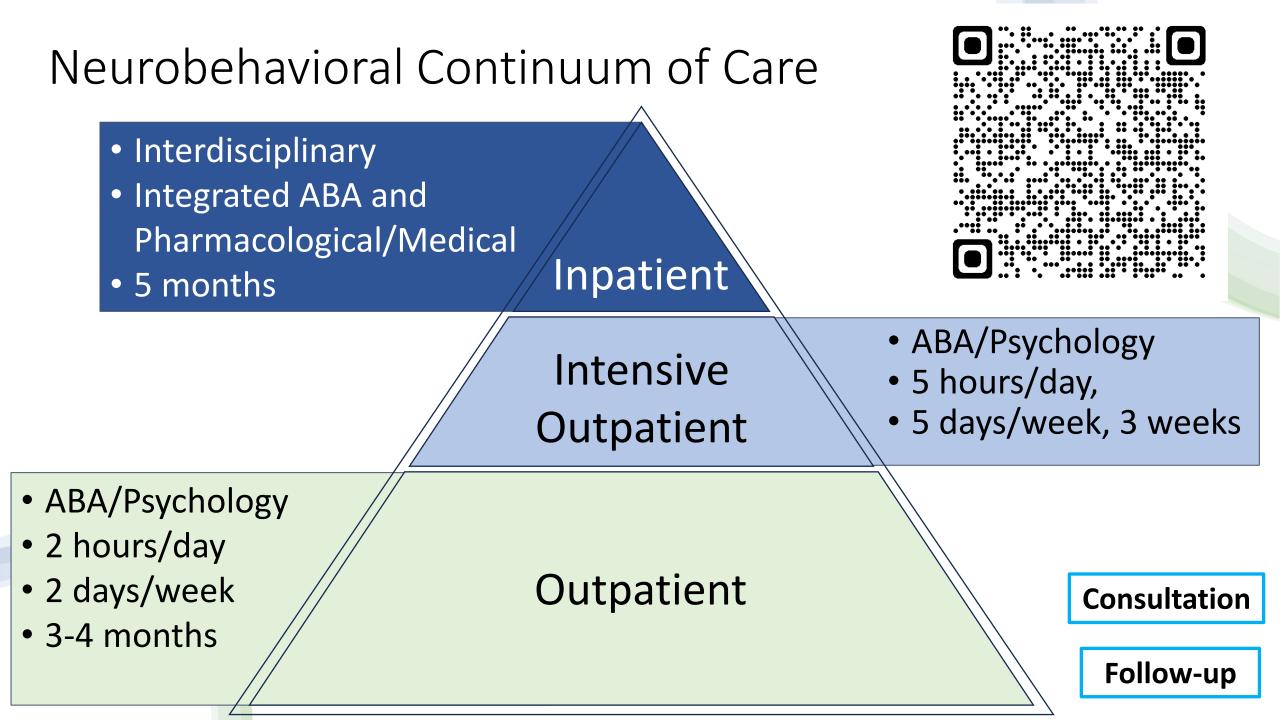


### Outpatient and Intensive Outpatient



### **Inpatient NBU**





# Factors Considered Determining the Level of Service

### Primary Clinical Variables

- Severity of challenging behavior (impact on functioning, injuries)
- Resistance to treatment
- Current and past services tried
- Services available locally
- Behavioral, medical, nursing care needs

### Other factors

- Caregiver goals and priorities
- Placement
- Insurance: Public; and Private
- Staffing resources
- Past services

### The Continuum of Services: • most severe and treatment-resistant problems **Clinical** Criteria

Intensive Outpatient

Inpatient

### Outpatient

- at high risk for injury or are injured
- requires intensive management
- not safe to transport to the clinic
- Have had inpatient/outpatient services
- may need pharmacological intervention for psychiatric targets
- more severe and treatment-resistant
- requires rapid treatment
- safe to transport to the clinic
- have had prior outpatient services
- moderate severity
- safe to transport
- services have been limited to date

### Approach to Treatment

Applied Behavior Analysis for all Neurobehavioral Programs

• And can co-treat or consult with other disciplines as needed

For NBU Inpatient – ABA is integrated within interdisciplinary treatment

- The "Neurobehavioral Model of Care"
- Functional Analysis and function-based treatment
- Pre-treatment stimulus assessments (Preference, Competition Assessments)
- Training Adaptive Skills: Communication, leisure skills, compliance, learning to wait, social skills

### Other Elements Common Across all Programs

- An emphasis on safety
  - Assessment of injuries and adverse events
  - Assessment of risks to self and others
  - Tactics to reduce risks
- Caregiver Involvement, Education & Empowerment

- Collaboration
  - with other Clinical Programs and Entities (State Agencies, Schools, Insurance Companies)

	Management of Challenging Behavior	<i>Treatment</i> of Challenging Behavior
<u>Primary Goal:</u>	Prevention of problems/ injury reduction	<i>Therapeutic behavior change,</i> independence, skill development
<u>Focus:</u>	On the present	On the present <b>and the future</b>
<u>Acceptability:</u>	Acceptable in the short term - while treatment is being developed, or as an adjunct when treatment is not sufficient. <i>Unacceptable</i> if used in the absence of treatment	Acceptable when necessary for safety, well-being, and quality of life. Must be consistent with evidence based practices, minimally restrictive, and allow for choice and self-determination

### Inpatient

Intensive Outpatient • most severe and treatment-resistant problems

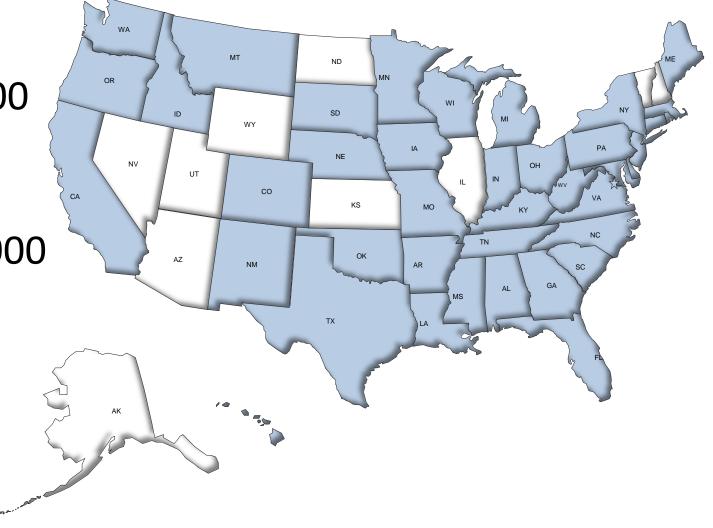
- at high risk for injury or are injured
- requires intensive management
- not safe to transport to the clinic
- Have had inpatient/outpatient services
- may need pharmacological intervention for psychiatric targets

Outpatient

### Patients Served

NBU IP has served over 1,000 patients from 40 states

NBU OP has served over 3,000 outpatients



Optimizing Treatment of Challenging Behavior by Personalizing Treatment for Each Individual: Combined and Targeted Application of Medical, Pharmacological, and Behavioral Interventions

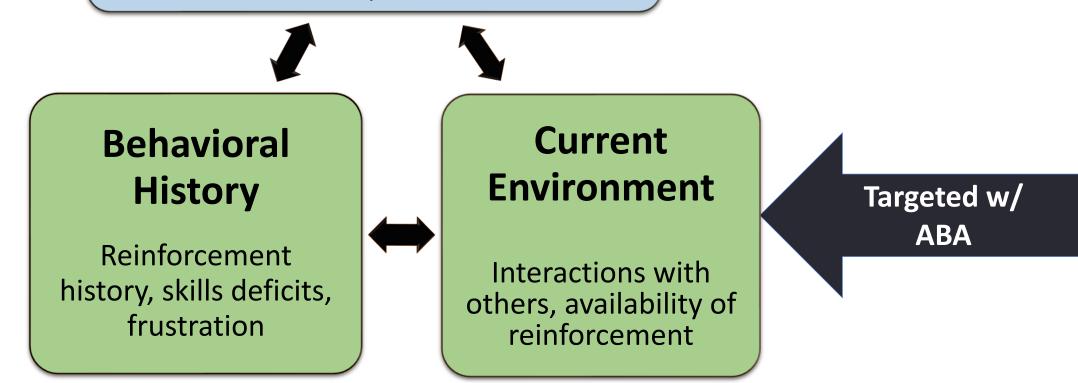
The Neurobehavioral Model of Care

# Neurobehavioral Model of Care

### **Biological Variables**

Psychiatric conditions, irritability, emotion dysregulation, genetic syndromes, neurological or medical problems

### Targeted w/ Medication or Medical Treatment



## Resources Required for More Severe and Treatment Resistant Challenging Behavior

- A dedicated Interdisciplinary Team, and Model of Care
- Specialized facilities, protective equipment for staff and patients
- Systems for Monitoring Injuries and taking swift preventative action
- Well-Described Behavior Management Procedures
  - To prevent injuries to staff from aggression
  - To prevent patient injuries related to self-injury, elopement, pica, aggression
- Methods to Train Staff and Ensure Competency
  - Didactic instruction and competency assessments (written)
  - Demonstration of skills (physical demonstration of competency)
  - Annual competencies to ensure skills are maintained
  - Ongoing feedback and coaching

## Conclusions

### Providing Personalized Treatment for challenging behavior:

- Requires we recognize the heterogeneity of challenging behavior in NDD
- Match the level of service to the individual's need
- Individualize behavioral interventions
  - based on the function of behavior, and the individual's skills and preferences
  - and train caregivers to high levels of proficiency
- Individualize pharmacological treatment
  - based on specific diagnoses and targets for medications and knowledge of the function

## Thought Leadership Summit on Challenging Behaviors



## Thought Leadership Summit on CHALLENGING BEHAVIORS

Staff Training QR Code



Severe Beh. Program QR Code



Evidence Based Practices QR Code



## Thank You!

Building Capacity & Competency for Individuals with Neurocognitive Disorders & Neurodevelopmental Disabilities: Long-Term Care Supports

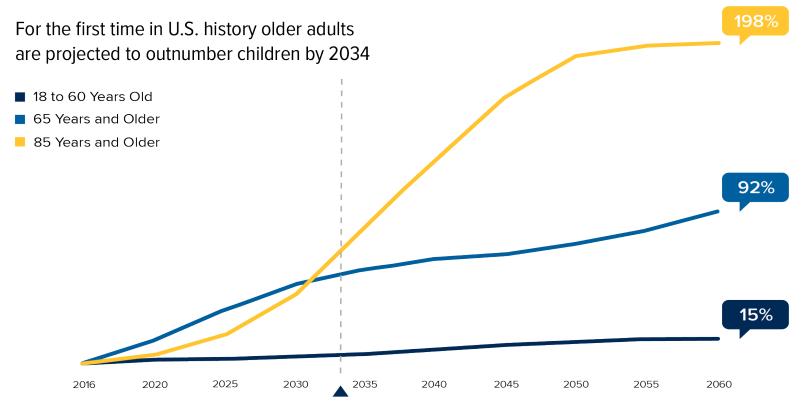
## August 15, 2024



Virginia Assisted Living Association (VALA)

### Aging Population

### **PROJECTED POPULATION GROWTH BY AGE GROUP, 2016 TO 2060**

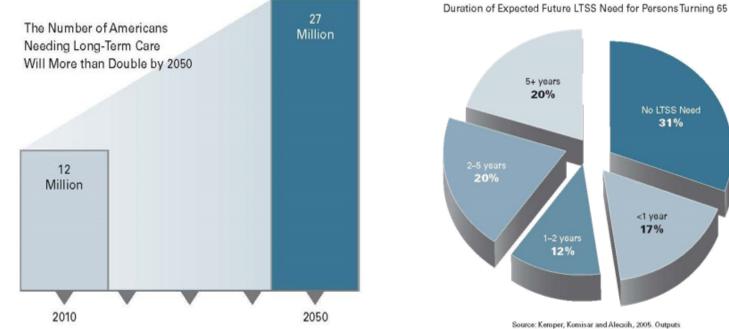


Source: Argentum 2024



### Looking Ahead: The LTC Challenge

### <u>"More than two-fifths</u> of baby boomers don't have any retirement savings," 2020 Census



Source: S. Kaye, C. Harrington, and M. Laplante (2010). Analysis of 2005 SIPP, 2007 NHIS, 2007 ACS, 2004 NHHS, and the 2005–2006 Medical Expenditure Survey

Source: Kemper, Komisar and Alecxih, 2005. Outputs of model using March 1993 and March 1994 CPS data

#### Source: Argentum 2024



## Long-Term Care Housing Supports for Adults (in addition to hospitals)

- Independent Living
- Assisted Living\*
- Nursing Home\*
- Group Home
- Other Long-Term Care Options
  - In-home Care at Private Residences
  - Respite Care

## \*Memory Care can be included in assisted living and nursing homes



### Long-Term Care Housing for Adults

Every setting level has a purpose and is needed, but they must work collaboratively and be accessible.

Making resources available *and known about* for challenging patients/residents can lead to better placement within the right settings.



### Senior Living Capacity Comparison Assisted Living Facilities & Nursing Homes



Data sources:

Assisted Living Facilities: VA Department of Social Services 08/14/2024 Nursing Homes: VA Department of Health Division of Long-Term Care Services 1/17/2024



### Assisted Living - Definitions

### 22VAC40-73-10

"Assisted Living care" means level of service provided by an assisted living facility for adults who may have physical or mental impairments and require at least moderate assistance with the activities of daily living. Included in this level of service are individuals who are dependent in behavior pattern (i.e., abusive, aggressive, disruptive) as document on the uniform assessment instrument"

"Assisted Living facility" means... any congregate residential setting that provides or coordinates personal and health care services, 24hour supervision, and assistance (scheduled and unscheduled) for the maintenance or care for or more adults who are aged or infirm or who have disabilities and who are cared for in a primarily residential setting.



### Assisted Living - Definitions

### 22VAC40-73-310-H

...assisted living facilities shall not admit or retain individuals with any of the following condition or care needs:

9. Individuals requiring continuous licensed nursing care.

### 22VAC40-73-10

"Continuous licensed nursing care" means around-theclock observation, assessment, monitoring, supervision, or provision of medical treatments provided by a licensed nurse.



### Long-Term Care Costs

## Genworth Cost of Care Survey 2023 – National Averages for Monthly Median Costs

www.genworth.com/aging-and-you/finances/cost-of-care

- Nursing Home Private Room: \$9,733
- Nursing Home Semi-private room: \$8,669
- Assisted Living Private Room: \$5,350
- Home Health Aide 24/7: \$24,024



### Long-Term Care Costs

### Genworth Cost of Care Survey 2023 – Virginia Averages for Monthly Median Costs

www.genworth.com/aging-and-you/finances/cost-of-care

- Nursing Home Private Room: \$10,190
- Nursing Home Semi-private room: \$9,247
- Assisted Living Private Room: \$6,050
- Home Health Aide 24/7: \$21,840

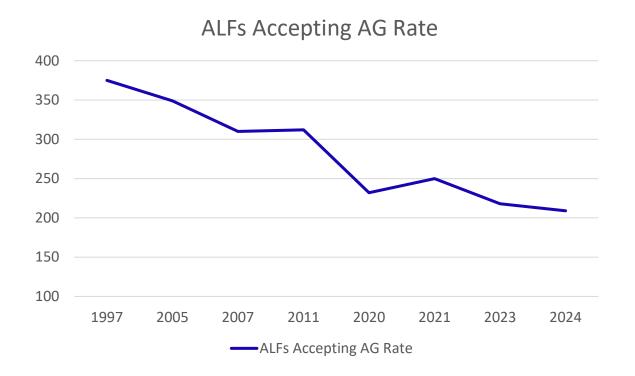


## Assisted Living - Funding

- Private Pay
- Long-Term Care Insurance
- Veteran's Aid & Attendance Benefit
- Auxiliary Grant (AG) SSI Supplement
  - \$2,079 for most of Virginia
  - \$2,391 for Planning District 8
- Discharge Assistance Program (DAP)
- No Medicaid Waiver for Assisted Living in Virginia



### Auxiliary Grant Acceptance



**Population Need:** Virginia NEEDS more assisted living facilities accepting the AG rate. Increasing the rate to <u>cover</u> the cost of care will INCREASE the number of participating ALFs



### Medicaid as a Resource for Funding

- Medicaid Waivers Do not cover ALFs in Virginia www.dmas.virginia.gov/for-providers/long-termcare/waivers/
  - Virginia Alzheimer's Waiver Assisted Living Waiver (terminated 6/30/2018)
  - CMS has approved Medicaid Waivers with assisted living as a Home & Community Based Setting (HCBS)
    - At least 38 states approved for Medicaid Waivers for assisted living services



### Building Capacity & Competency Next Steps

### How to Increase Provider Participation...

- Review funding and support programs to make sure assisted living is included as setting option
- Change payment allocation for Auxiliary Grant to be a true supplement instead of a subtraction
- Provide informational trainings to licensed providers on available resources to support challenging placements (i.e. DAP funding, social worker supports)





### Virginia Assisted Living Association



## Questions? Comments?

Contact VALA... Judy Hackler VALA Executive Director (804) 332-2111 <u>jhackler@valainfo.org</u> <u>www.valainfo.org</u>



## HB 888 / SB 176: Serving Individuals with Brain Injuries, Dementia, and Co-Occurring Disorders

AUGUST 15, 2024



Case Study

#### Violent Dementia Patients Leave Nursing Home Staffers and Residents 'Scared to Death'

By Jordan Rau; Published in NPR on August 8, 2024

Dan has vascular dementia. At home, he had been getting lost, having outbursts, and leaving the gas stove on. As the disease progressed, his outbursts became hard to handle. He took a swing at one of his sons when he was upset about the temperature in the house. He refused to swallow his medications and fell repeatedly. His family moved him to a nursing home.

Jeffrey has dementia with behavioral issues, major depressive disorder with psychotic features, and hypertension. His dementia reportedly stemmed from excessive and long-term alcohol use. He had previously been hospitalized for being confused, suicidal, and agitated. He had moved from one nursing home to another to be closer to his brother.

In a nursing home where they both ultimately resided, Dan, carrying a knife and fork, walked over to a dining room table where Jeffrey was sitting. Jeffrey told Dan to keep the knife away from his coffee. Dan, who at 5-foot-2 and 125 pounds was half Jeffrey's weight and 10 inches shorter, turned to walk away, but Jeffrey stood up and shoved Dan so hard that when he hit the floor, his skull fractured and brain hemorrhaged. He died five days later.

Link: https://www.npr.org/sections/shots-health-news/2024/08/08/nx-s1-5066969/dementia-violence-violent-patient-nursing-homes



## Co-Occurring Conditions: Dementia & BH

Patients with dementia had markedly increased risks of psychiatric disorders both before and after dementia diagnosis.

• Mo, et al. , 2023, doi:10.1001/jamanetworkopen.2023.38080

Mental disorders were associated with the onset of dementia in the population.

• Richmond-Rakerd, et al., 2022, doi: 10.1001/jamapsychiatry.2021.4377

Psychiatric disorders are associated with increased risk of subsequent dementia.

• Stafford, et al., 2022, doi: 10.1002/gps.5711

Odds of dementia diagnosis are significantly greater for beneficiaries diagnosed with schizophrenia, bipolar disorder, and major depressive disorder.

• Brown & Wolf, 2017, doi: 10.1177/0164027517728554



## Co-Occurring Conditions: BI & BH/SUD

One out of five people presenting for treatment of a substance use disorder is also living with the effects of brain injury.

• Lemsky, 2021, Traumatic Brain Injury and Substance Use Disorders: Making the Connections

As many as 75% of the people seeking services for concurrent mental health and substance use disorders are living with the effects of brain injury.

- TBI was associated with current alcohol use and psychiatric symptom severity and with lifetime institutionalization and homelessness.
- It was more common among participants with posttraumatic stress disorder, borderline personality disorder, and antisocial personality disorder.
- McHugo, et al., 2017, doi: 10.1097/HTR.00000000000249

Adults with brain injuries had increased odds of screening positively for elevated psychological distress.

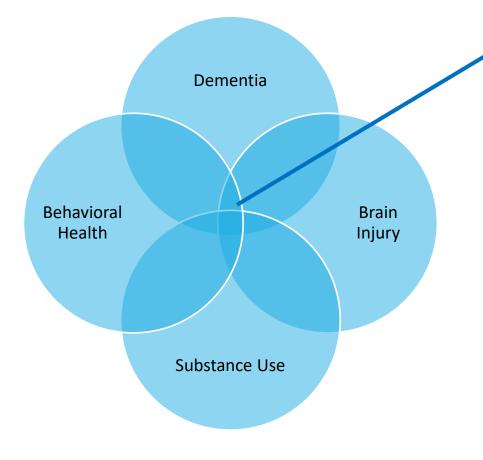
• Ilie, et al., 2015, doi: 10.1089/neu.2014.3619

A history of one or more brain injuries with loss of consciousness is associated with greater symptom complexity, including more psychiatric symptoms and a significantly elevated risk of suicide.

• Corrigan, et al., 2012, doi: 10.3109/02699052.2011.648705



## Crisis Services: Symptoms Can Overlap



In a crisis, the cause of behaviors or symptoms is not always known or readily distinguishable, and the behaviors and symptoms can stem from a variety of diagnoses.



# Without Access to Appropriate Crisis & Long-Term Care Placements

### Individuals can end up:

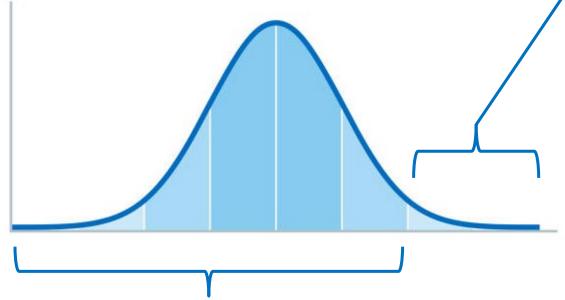
Stuck in EDs/hospitals Taken to local jails/criminal justice system

### Homeless



## Long-Term Care Services

#### Individuals with Neurocognitive Disorders: Symptom Complexity



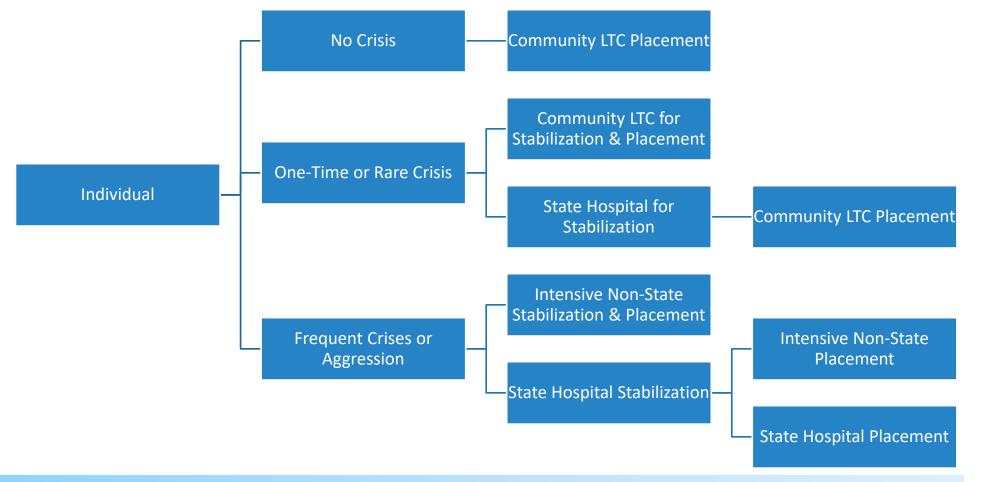
Individuals with severe behavioral and psychological symptoms (either due to a singular but intensive neurocognitive disorder diagnosis or due to the interplay of cooccurring conditions) may need more intensive or alternative LTC services that are not:

- Permitted,
- Offered,
- Reimbursed/Covered, or
- Safe for other residents and staff in standard HCBS or LTC settings.

Can (and are) being served successfully in existing, standard HCBS & LTC settings.



## How The Process Could Unfold





## Common LTC Services Barriers in Virginia

#### Barrier: Individual's History

- Behaviors
- Criminal record
- Substance use
- Lack of family support

#### Barrier: Income/Assets

 Income is too high and/or assets are too extensive to qualify for Medicaid LTC, but also too low to cover the costs for LTC privately

#### Barrier: Care Needs

 Individuals do not meet Virginia's Medicaid nursing facility level of care, but they cannot be safely served in other HCBS or LTC settings

#### Barrier: Combination Barriers

• The ultimate crisis and LTC services gap.



## **DARS** Services

BI Case Management or Dementia Care Coordination (AAAs and BI Providers)

- Limitations:
  - Not available 24/7
  - Dementia CC is not available in all areas of Virginia
  - Delayed time to access (e.g., waitlist, assessment, approval process)
  - Limited funding and services are not guaranteed
  - Not a "hands on" care service

In-Home or Home-Based Services (AAAs and LDSS)

- Limitations:
  - Not available 24/7
  - Not available in all areas of Virginia
  - Delayed time to access (e.g., waitlist, assessment, approval process)
  - Limited funding and services are not guaranteed
  - Needs to reside in the community

Decision-Making through the Public Guardianship & Conservatorship Program (PGP Providers)

- Limitations:
  - Delayed time to access (e.g., waitlist, approval process)
  - Limited funding and services are not guaranteed
  - Not a "hands on" care service

None of these are designed to serve as Crisis Services or sustainable Long-Term Care Services. Providers call 9-1-1 or 9-8-8 for immediate assistance.



## Opportunities

Embrace	<ul> <li>Acknowledge Needs</li> <li>Identify What Is Working</li> </ul>	
Expand	<ul> <li>Scale Pilot Programs, like RAFT and CSB/Provider Partnerships</li> </ul>	
Evolve	<ul> <li>Virginia's Behavioral Health System through Training and Staffing</li> </ul>	



## **Contact Details**

Catherine Harrison Director of Policy & Legislative Affairs Virginia Department for Aging and Rehabilitative Services Phone: (804) 662-9968 Email: Catherine.harrison@dars.virginia.gov Website: dars.virginia.gov





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

Secretary of Health and Human Resources Thursday, August 29, 2024 | 10:00 a.m. – 12:30 p.m. Location: DARS with Virtual Option

In Person	
Leah Mills, HHR Deputy Secretary	Judy Hackler, VALA
Braden Curtis, DBHDS	Catherine Harrison, DARS
Alexis Aplasca, HHR & DBHDS	Aimee Perron Seibert, VCEP
Ann Bevan, DMAS	Christine Schein, VHHA
Jae Benz, DBHDS	Dana Parsons, Leading Age
Karin Addison, Neuro Restorative	Joshua Myers, Alzheimer's Association of
Brain Injury Facility	Virginia
Jennifer Faison, VACSB	Byron Wine, The Faison Center
Jonathan Green, OES	Nicole Durose, DLCV
Brian Kelmar, Parent Advocate	Joran Sequeira, VCEP
Jason Young, VABIAV	
Online	
Senator Barbara Favola	Delegate Vivian Watts
Martin Mash, VOCAL	Steve Ford, VACA-VCAL
Bruce Cruzer, MHV	James Murphy, VHHA
Suzanne Mayo, DBHDS	Heather Norton, DBHDS
Keith Hare, VHCA-VCAL	Tonya Milling, ARC of VA
Meghan Cox, DARS	Deborah Dashiell, Western Tidewater CSB
Lucy Beadnell, ARC of NOVA	Nathalie Molliet-Ribet, BHC
Mark Smallcombe, VCU Health	Cimberly Ayers, Wythe County DSS
Sarah Harris, Parent Advocate	Annette Clark, DBHDS
Sarah Rexrode, Franklin County	Dev Nair, DBHDS
DSS	
Brian Unwin, Carilion Clinic	

#### **DRAFT MINUTES – Meeting Three**

#### Welcome – HHR Deputy Secretary Leah Mills

HHR Deputy Secretary Leah Mills welcomed and thanked all of the participating workgroup members and members of the public for volunteering their time to this critical effort. She reviewed major take aways from the last meeting and key themes discussed to guide recommendations. Deputy Secretary Mills noted the 25<sup>th</sup> anniversary of the *Olmstead* decision and emphasized choice, dignity, and least restrictive environments as guiding principles for the workgroup. She reminded the workgroup of a question posed during the previous meeting – "What does success look like?" – and emphasized the importance of continuing to keep the needs identified by individuals with lived experience and their supporters at the center of the workgroup's decisionmaking.

#### **Stakeholder Perspective – Youth in Foster Care**

Rebecca Morgan, with the Virginia League of Social Service Executives representing local departments of social services across Virginia, shared the challenges faced in finding placements for children in foster care with high acuity behavioral health needs who often have co-occurring neurodevelopmental and neurocognitive diagnoses. Ms. Morgan reviewed the success of the Safe and Sound Taskforce in decreasing the incidents of children in foster care staying in hotel rooms and offices due to lack of available placements. She noted that oftentimes these children had significant trauma associated with abuse and neglect which contributed to their behavioral challenges. She emphasized that in crisis situations it is often impossible to conclusively determine whether behaviors are rooted in trauma, mental illness, traumatic brain injury, developmental disability, or a combination. She pointed out the importance of exploring additional providers and community structures to better address the needs of children with complex diagnoses and reminded everyone of the need to ensure that the recommendations addressed the needs of youth.

#### **Opportunities to Improve System Infrastructure – Partner Perspectives**

### Suzanne Mayo, Division of Facility Services, Department of Behavioral Health and Developmental Disability Services (DBHDS)

Suzanne Mayo provided the workgroup with an update on the case referenced in the stakeholder perspective shared at the previous meeting by the Brain Injury Association of Virginia (BIAV), which revealed challenges in communication and coordination between the hospital and community brain injury services. Following that meeting, the patient signed a release allowing DBHDS staff at Central State Hospital to communicate with BIAV case managers, and they are collaborating to support the patient. Ms. Mayo noted that the Code of Virginia has a provision permitting state hospitals to share patient information with Community Services Boards (CSBs) without a patient release. Patient information can also be shared with legal guardians and those under certain forms of power of attorney. She conveyed, however, that state hospitals cannot share patient information with other entities without a patient release, and if a patient is not able to identify community providers that they have received services from, the state hospital has no way of knowing which entities to request a release for. Ms. Mayo stressed the importance of

improving communication barriers, particularly when individuals with disabilities cannot share their own information.

Ms. Mayo then reviewed recommendations from a recent study conducted by Berry Dunn to support implementation of rates for the Discharge Assistance Program (DAP). One requirement of the study was to recommend training for assisted living facilities (ALFs), skilled nursing facilities, and nursing homes accepting patients from state facilities. The main finding of the study was that there was a need for training in best practices for deescalating behaviors (ex: therapeutic options, crisis prevention, the Mandt System) to support patients, especially when they are first transitioning to the new service. The study also recommended training in Mental Health First Aid, Positive Approach to Care, or best practice in Dementia Care, and patient specific training.

#### Workgroup Discussion:

Jeannine Rosado shared her positive experience supporting her adult son with Autism receiving care from Central State Hospital. Workgroup members emphasized the importance of supporters and community providers communicating with clinicians in the emergency room before entering the hospital and recommended that the workgroup consider means of supporting this communication. Members noted the difficulty of identifying community providers serving the patient when the patient is unable to provide that information. Brian Kelmar noted that there are "code blues" for stroke patients and suggested a similar notification for individuals in crisis. This could be a way to flag an individual before they are at hospital so that appropriate personnel arrive for the initial incident, not after. Ms. Rosado added that police have responded four different times for her autistic son but that, even after telling them that her son had Autism, they would still go to a punitive solution instead of facilitating help appropriate to Autism.

#### Jae Benz, Office of Licensing, DBHDS

Jae Benz provided the workgroup with an overview of services licensed by DBHDS. She shared that DBHDS is working to ensure that licenses align with the type of services/supports provided rather than primary diagnosis of the individuals receiving the service. She also provided an update on the regulatory overhaul which will re-organize DBHDS licensing regulations to support the shift from a diagnosis-driven licensing structure to a service driven structure.

Ms. Benz then reviewed DBHDS support of the buildout of a comprehensive crisis continuum as the alternative to inpatient psychiatric care based on the "no-wrong door" model, which can address the needs of anyone experiencing a mental health crisis regardless of primary diagnosis. She also provided information on how the REACH program is being incorporated into the comprehensive crisis continuum. REACH is designed to meet the crisis support needs of individuals with developmental disabilities who are experiencing behavioral health or behavior-related crisis events.

Ms. Benz also reviewed how private inpatient psychiatric services are licensed. She emphasized that if an individual with a neurodevelopmental disability or neurocognitive disorder is

experiencing a mental health crisis there is no prohibition against their admission into inpatient services and this should not be a basis for exclusionary criteria. Finally, Ms. Benz reviewed existing regulations providing for the licensing of specialty services including gero-psychiatric residential services, usually for individuals 65 and older. She noted that there are no existing active licenses for the provision of gero-psychiatric residential services. Ms. Benz identified possible barriers to providers starting this service including requirements for staff qualifications and funding sources.

#### Workgroup Discussion:

Workgroup members emphasized that REACH services are often at capacity and cannot always admit individuals with aggressive behaviors. It was noted that efforts are being made to cross train all REACH service providers and crisis service providers to increase their capacity to support individuals with co-occurring neurodevelopmental disabilities across the continuum. Jae Benz noted that REACH is specialized for DD but that anyone can go to a CSU. Ms. Benz also noted that all providers are required to be trained in behavioral issues and that CSUs can now provide seclusion, with strict requirements. Jeannine Rosado replied that the only protocol in place was for REACH and that she had not looked into a CRC.

Workgroup members participating virtually in the chat noted that oftentimes for older adults experiencing behavioral and psychological symptoms of dementia (BPSD), the mental health crisis is linked to co-morbidities and medical factors requiring a combined "medical" and "mental health" intervention. Co-occurring medical conditions may also contribute to behavioral crisis experienced by younger individuals with neurodevelopmental disorders.

#### Dr. James Murphy, Virginia Hospital and Healthcare Association

Dr. James Murphy presented an overview of barriers and recommendations for supporting individuals with neurodevelopmental and neurocognitive disorders and significant behavioral challenges. He noted these disorders are extremely broad diagnostic categories, and individuals require specialized treatment that is typically different than what is provided on acute inpatient hospital units. Identifying care needs requires consideration of verbal skills and cognitive functioning and how it has changed over time as well as behaviors and potential safety risks. Individuals within these populations may need behavioral focused treatments. He noted that occupational therapy plays a key role in addressing ADLs, and staff support ratios of 2:1 or 1:1 are essential to meet both behavioral and ADL requirements; coverage for these costs, however, is challenging for insurance providers.

Because of staffing needs to ensure safety, supporting individuals in these populations with high acuity needs can increase staff burnout especially if a facility is already understaffed. These populations also have increased lengths of stay due in part to the lack of appropriate discharge placements. REACH services play an essential role in supporting those with neurodevelopmental disabilities; however, these services are often at capacity and are not always appropriate step-down placements, and there is a clear need for more comprehensive therapeutic interventions in addition to REACH. There are also often additional requirements for discharge planning that contribute to the extended length of stay (ex: Uniform Assessment Instrument (UAI),

guardianship). When an individual has a primary diagnosis of neurodevelopmental disability or neurocognitive disorder it can also be challenging to prove that behavior has changed enough from baseline to get an insurer to cover the cost of treatment especially if changes have occurred over a more extended period of time.

Dr. Murphy's recommendations to support included increased reimbursement rates for providers to cover increased staffing needed for these populations; funds for additional community-based providers including group homes, assisted living facilities, and nursing homes that specialize in working with these populations; grant funds to private providers/hospitals to open specialty units for each of these distinct populations; development of additional respite care and crisis service capacity including specially trained mobile crisis teams; additional resources and support for nursing and group home staff to better support patients to reduce the need for hospitalization; and development and implementation of a program modeled after VMAP to assist primary care providers in learning best practices and medication management.

#### Keith Hare and Steve Ford, Virginia Health Care Association (VHCA)

Keith Hare and Steve Ford presented on behalf of the VHCA. Mr. Hare emphasized the need for expanding capacity of specialized placements for individuals with neurodevelopmental disabilities noting that they are sometimes placed in assisted living facilities and nursing homes and this may not be appropriate to their needs. He emphasized the importance of supporting and expanding current pilot programs and public-private partnerships. These partnerships between CSBs and private providers include the creation of specialized units for people with high acuity needs and training for staff to support people remaining in their current treatment setting. Mr. Hare noted that unlike many other states, Virginia does not have a rate add-on to help support training staff and build the infrastructure needed to support patients with high acuity behavioral health support needs. The current pilots receive standard Medicaid reimbursement rates, and CSB provide additional staff augmentation in kind.

Mr. Ford reviewed how periodic needs assessments inform the care plan and identify resource needs which in part determine reimbursement. He stated that the current Resource Utilization Groups (RUG) in the Medicaid assessment used to determine rates do not adequately reflect behavioral health needs. As a result, facilities face lower reimbursement rates despite significant needs and costs, as Medicaid scales fail to account for these complexities. Virginia Medicaid is currently modifying the payment methodology due to federal changes with a target date of implementation in approximately 15 months. He relayed VHCA's concerned that, while the proposed changes would be an improvement, they still will not fully account for the behavioral support needs of the patients.

Mr. Hare and Mr. Ford noted that the Valley Health Care Center in Chilhowie has been successful despite the lack of Medicaid enhancements. They recommended standing up regional hubs to support public-private partnerships for creating and expanding specialized placements for individuals with neurocognitive disorders and high acuity behavioral challenges. Organizing administration at the regional level would support consolidation of resources and achieve economies of scale. In order to be sustainable, the specialization of these programs needs to be reflected in the reimbursements they receive.

#### Jonathan Green, Department of Magistrate Services, Office of the Executive Secretary

Jonathan Green, speaking on behalf of the Office of the Executive Secretary, discussed the statutory requirements of the TDO process noting that the TDO process is the last part of the involuntary commitment process that the magistrate is involved in. Mr. Green emphasized that the TDO process is significantly different than the involuntary commitment hearing process. Involuntary commitment hearings are scheduled in advance and respondents have a right to legal council, but TDO hearings are held as the need arise. He noted that magistrates seldom have direct contact with the individual in crisis and rely on the information provided by other sources to make this judgment. Sources of information are most commonly CSB staff but also family, treating physicians, and medical records if they are available. The availability of medical records depends on timing.

The language proposed in HB888/SB176 would prevent magistrates from issuing a TDO if they determine that there is probable cause to believe that behaviors are solely the manifestations of neurocognitive or neurodevelopmental disorders. Mr. Green reminded the workgroup that magistrates are not clinicians or diagnosticians and there is an opportunity to train magistrates to understand that ND and NC do not equate to mental illness under the law. He also noted that magistrates evaluate evidence presented to them and apply the law to the evidence; a primary challenge is obtaining sufficient information to determine whether the symptoms or behaviors are exclusively caused by ND/NC conditions. Mr. Green noted that if the legislation is reenacted there will likely be significant challenges for magistrates to receive sufficient information to determine whether there is probable cause to believe that the behavior is solely the manifestation of a ND or NC disorder. This determination will be challenging for magistrates to make and there oftentimes may not be a clear right answer.

#### Workgroup Discussion:

Workgroup members emphasized that oftentimes prescreeners do not have placement options for people with co-occuring neurodevelopmental or neurocognitive disorders and high acuity behavioral challenges. Members shared that REACH has significant capacity limitations and is only for voluntary patients. It was noted that the TDO process is currently the only tool that prescreeners have to support individuals in these populations who are determined to be a significant danger to themselves and/or others. Members participating virtually noted in the chat the importance of identifying how to create opportunities for better information exchange from family members and assessments.

#### Jennifer Faison, Virginia Association of Community Services Boards (VACSB)

Jennifer Faison spoke on behalf of VACSB. She reviewed potential implications of reenacting the bill language without amending. Ms. Faison noted most private facilities have exclusionary criteria prohibiting admission of these individuals. As written, the bill will not allow these individuals to be admitted to state hospitals regardless of whether they are an active danger to themselves and/or others and no alternative safe setting exists to care for them. Ms. Faison noted that, in a moment of crisis, there may not be strong evidence indicating whether behaviors are

due to mental illness or solely a neurodevelopmental or neurocognitive disorder. Individuals may not be known to the CSB prior to their prescreen, and if the individual is not able to speak to their medical history and previous diagnosis during a crisis, it is unknown how this determination will be made.

Ms. Faison noted the expansion of mobile crisis will mitigate some of the issues identified by the workgroup. Mobile crisis teams are being cross-trained: REACH mobile teams are being trained to support individuals with primarily behavioral health needs, and mobile crisis teams are being trained to support individuals with developmental disabilities and co-occurring behavioral health challenges. Continuing to enhance REACH capacity as a specialized service is essential, as well as supporting collaboration between REACH and CRCs.

Ms. Faison emphasized that the criminal justice involvement of individuals and need for expanding diversion programs is also important to consider in developing recommendations. The state engaged in sequential intercept model cross systems mapping a number of years ago. This initiative supported the implementation and expansion of REACH and CITACs. Additionally, she pointed out the necessity of proximity for assessment centers that facilitate law enforcement drop-offs and the importance of a dedicated workforce and providers to support these efforts. Ms. Faison also addressed the need for increased funding to match the capacity and current demands of divergent programs like REACH and CRCs, which have not seen funding adjustments since they were first established 15 years ago. Finally, Ms. Faison noted that years ago there was discussion of a pilot for a CSB to work with a private hospital to develop a specialized in-patient unit for treating individuals with neurodevelopmental disabilities. She stated that CSBs are open to these kinds of partnerships but we need to figure out how to expand them to scale and make them sustainable.

#### Workgroup Discussion:

The workgroup expressed concern about events when an individual is experiencing a behavioral crisis and is an active danger to themselves or others but there are no safe alternatives available outside of an inpatient setting. Access to such placements is needed as a last resort.

Brian Kelmar noted the need to divert individuals before they are brought to a magistrate is crucial, as TDOs are often not the appropriate solution for many members of this population. The focus should be on finding alternative interventions to address their needs prior to the point of magistrate involvement. This would help ensure that individuals receive appropriate care and are not diverted into the criminal justice system.

#### **Public Comment:**

Lucy Beadnell, Arc of Virginia – Ms. Beadnell noted that there are times when people have a developmental disability but have never been formally diagnosed. Such individuals may get caught in the criminal justice system without access to needed services because the screenings used to identify mental health needs are not designed to and do not identify developmental disabilities.

Theresa Champion, Virginia Autism Project – Ms. Champion highlighted that inpatient treatment in state hospitals can be traumatic and is not the appropriate placement for some individuals with NDD and there are insufficient community-based services. Ms. Champion suggested that, when recommendations are presented, the workgroup discuss each real life case example presented throughout the meetings in light of the recommendations to determine if they meet the needs identified.

#### **Review Preliminary Recommendation Topic Areas and Group Discussion**

Deputy Secretary Mills noted themes that emerged from this meeting. Needs including:

- Improved communication to ensure effective information exchange among stakeholders
- Diversion strategies to redirect individuals from inappropriate settings to more suitable care environments
- Comprehensive training programs for those involved in managing individuals with special needs, including cross-training among professionals
- Ensuring adequate resources for individuals and the systems
- Expanding and building out the system will help to better accommodate and support those in need
- Implementing evidence-based models to guide practices and interventions
- Providing robust support for caregivers to enhance their ability to effectively manage and support individuals in their care

Workgroup members discussed the need to create and expand more state partnerships with group home providers. It was noted that group homes are legally permitted to refuse to allow individuals seeking to return to services after going to the emergency department even if the individual was not placed under a TDO. It was discussed that this typically happens because the provider does not feel that they have adequate staffing or training to provide services.

Workgroup members noted that every Medicaid recipient receiving long-term care services has a planner responsible for the coordination of their care. There may be opportunities to support these professionals in connecting members to mental health services as one of their covered benefits. Some workgroup members also recommended expanding the types of service settings covered under Medicaid, including Assisted Living Facilities (ALFs).

#### Adjourn

Deputy Secretary Mills provided closing remarks and shared tentative dates for the next meeting.





Licensing Structure of the DBHDS Office of Licensing

Jae Benz, Director





# Provider

"Provider" means, as defined by § 37.2-403 of the Code of Virginia, **any person, entity, or organization**, excluding an agency of the federal government by whatever name or designation, that **delivers (i) services to individuals with mental illness, developmental disabilities, or substance abuse (substance use disorders) or (ii) residential services for individuals with brain injury.** The person, entity, or organization shall include a hospital as defined in § 32.1-123 of the Code of Virginia, community services board, behavioral health authority, private provider, and any other similar or related person, entity, or organization. It shall not include any individual practitioner who holds a license issued by a health regulatory board of the Department of Health Professions or who is exempt from licensing pursuant to §§ 54.1-2901, 54.1-3001, 54.1-3501, 54.1-3601, and 54.1-3701 of the Code of Virginia.

# Service

"Service" means, as defined by § 37.2-403 of the Code of Virginia, (i) planned individualized interventions intended to reduce or ameliorate mental illness, developmental disabilities, or substance abuse (substance use disorders) through care, treatment, training, habilitation, or other supports that are delivered by a provider to individuals with mental illness, developmental disabilities, or substance abuse (substance use disorders). Services include outpatient services, intensive in-home services, medication assisted opioid treatment services, inpatient psychiatric hospitalization, community gero-psychiatric residential services; assertive community treatment and other clinical services; day support, day treatment, partial hospitalization, psychosocial rehabilitation, and habilitation services, crisis stabilization, and other residential services; and supportive residential, special school, halfway house, in-home services, crisis stabilization, and other residential services; and supports the effects of brain injury through care, treatment, or other supports provided in residential services for persons with brain injury.



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### **Short-Term more intensive Services**

- Mental health partial hospitalization
- Medically monitored intensive inpatient treatment or Level of care 3.7
- REACH Crisis Therapeutic Home
- REACH mobile crisis response
- Clinically managed high-intensity residential care or Level of care 3.5
- Clinically managed population specific high-intensity residential or Level of care 3.3
- Community-based crisis stabilization
- Crisis receiving center
- Crisis stabilization unit
- Inpatient psychiatric
- Respite care
- Medically managed intensive inpatient service or Level of care 4.0
- Substance abuse partial hospitalization

### **Longer-Term Services**

- Intensive in-home
- Clinically managed low-intensity residential care or Level of care 3.1
- Substance abuse intensive outpatient
- Medication assisted opioid treatment
- Mental health outpatient
- Day support
- Day treatment, including therapeutic day treatment for children and adolescents
- Group home and community residential
- ICF/IID
- Community gero-psychiatric residential
- Assertive community treatment (ACT)
- Case management
- Mental health community support
- Psychosocial rehabilitation
- MH Residential treatment
- Sponsored residential home
- Substance abuse outpatient
- Supervised living residential
- Supportive in-home

- The Office of licensing supports individuals with mental illness, developmental disabilities, or substance use disorders as well as individuals with brain injury who require residential treatment services however the *licenses reflect the type of services/supports provided even more so than the diagnosis of the individual.* 
  - License both acute and longer-term services. Can be multiple points of entry into a service, and an individual might receive several services through multiple different providers based on their presenting needs.
  - Impetus has to move away from licensing regarding primary diagnosis, particularly for shorter term services.
    - $\circ~$  30-50% of individuals with a DD have a co-occurring mental illness
    - 38% of individuals with SU disorder have a mental illness
    - $\circ~$  18% of those with MI also have a SU disorder
  - Diagnosis is more of a consideration for longer term care services.

### **Examples**:

An individual may live in a Group Home, but also receiving outpatient counseling and supportive employment services and short-term community based mobile crisis services.

Individuals entering a substance use treatment program, may have co-occurring diagnosis butt the individual entering the SU service has as their primary service need – substance use treatment.



- Regulatory Overhaul:
  - Restructure regulations
  - Will include one overarching 'General Chapter' that will apply to all providers and five 'service specific' chapters:
    - Residential, Non-Center Based
    - Center-Based
    - Case Management
    - Crisis
  - This methodology allows DBHDS to write more detailed service specific regulations that will assist providers in understanding exactly which regulatory provisions apply to their services



### Alternatives to Inpatient Psychiatric Care: Crisis Receiving Centers



#### **Goal of Service**:

 Assess crisis and psychosocial needs during the 23-hour service to determine the best resources available to the individual to prevent unnecessary hospitalization.

### **Provider Requirements:**

- Role of this services is to assess crisis and psychosocial needs during the 23-hour service to determine the best resources available to the individual to prevent unnecessary hospitalization.
- It is based on the premise that there is no wrong door for individuals having a mental health crisis.
- This includes accepting mental health crisis referrals for individuals of varying ages and clinical conditions, such as serious emotional disturbances, serious mental illness, and intellectual and developmental disabilities, regardless of acuity.



### Alternatives to Inpatient Psychiatric Care: Crisis Stabilization Units



#### Goals of Service:

- Stabilize the individual in a community-based setting
- "Crisis stabilization unit," "CSU," or "residential crisis stabilization unit" is a community-based, short-term residential treatment unit. CSUs serve as primary alternatives to inpatient hospitalization for individuals who are in need of a safe, secure environment for assessment and crisis treatment. CSUs also serve as a step-down option from psychiatric inpatient hospitalization and function to stabilize and reintegrate individuals who meet medical necessity criteria back into their communities
- Reduce an individual's acute symptoms
- Identify and mobilize an individual's available resources including support networks



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### Alternatives to Inpatient Psychiatric Care: REACH



### Goal of Service:

 The REACH program was established to provide a statewide crisis system of care that serves individuals diagnosed with a developmental disability (DD) who reside in Virginia. This system is designed to meet the crisis support needs of individuals with developmental disabilities who are experiencing behavioral health or behavior-related crisis events.

### **Core Services Offered:**

- > Mobile Crisis Response
- Community-Based Stabilization
- > Crisis Therapeutic Homes (Adults & Youth): services typically provided up to 15 days
- Prevention



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#### 7/10/24

Crisis Services Regulatory Training



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### Inpatient Psychiatric Service

"Inpatient psychiatric service" means intensive 24-hour medical, nursing, and treatment services provided to individuals with mental illness or substance abuse (substance use disorders) in a hospital as defined in § <u>32.1-123</u> of the Code of Virginia or in a special unit of a hospital.

- Individuals with a Developmental Disability or with a Major Neurocognitive Disorder (MND)/Dementia may also have a co-occurring mental illness and/or substance use disorders.
- The OL does not disallow or discourage an individual experiencing a mental health crisis who requires hospitalization to be admitted to a private hospital.
- Our expectations include that:
  - An individual be reviewed for the least restrictive environment.
  - The needs of the individuals being served inform program staffing.
  - The Office of Licensing does not track census or admissions/discharges in real-time that is monitored more by MCOs or private insurance companies.
  - OL concerns are typically the result of a complaint or incident we investigate.



### Inpatient Psychiatric Service

"Inpatient psychiatric service" means intensive 24-hour medical, nursing, and treatment services provided to individuals with mental illness or substance abuse (substance use disorders) in a hospital as defined in § <u>32.1-123</u> of the Code of Virginia or in a special unit of a hospital.

12VAC35-105-580. – provides expectations for providers related to being prepared to support individuals in the specific service for which they are licensed.

### Expectations include:

- Provider must outline how each service offers a structured program of individualized interventions and care to meet the individuals needs; provide protection, and supervision; and meet ISP objectives.
- written description of each service offered and include:
  - description of care, treatment, characteristics and needs of individuals to receive services
  - Admission, discharge and exclusion criteria
  - Type and role of employees or contractors
- Provider shall admit only those individuals whose service needs are consistent with the service description, for whom services are available, and for which staffing levels and types meet the needs of the individuals receiving services.



- New providers:
  - **OL supports state initiatives**
  - Work closely with providers who are interested to develop specialized programs to meet a specific need
  - Identify and address barriers, early on
  - Pull in other offices and agencies to work collaboratively with providers

### • Example: Community Gero-Psychiatric Residential Services

"Community gero-psychiatric residential services" means 24-hour care provided to individuals with mental illness, behavioral problems, and concomitant health problems who are usually 65 years of age or older in a geriatric setting that is less intensive than a psychiatric hospital but more intensive than a nursing home or group home. Services include assessment and individualized services planning by an interdisciplinary services team, intense supervision, psychiatric care, behavioral treatment planning and behavior interventions, nursing, and other health-related services.

- One of the requirements: Providers shall implement written policies and procedures that support an active program of MH and behavioral management services to assist each individual achieve outcomes consistent with the highest level of self-care, independence, and quality of life
- No service licensed for more than ten years





# **Questions?**



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

Secretary of Health and Human Resources Friday, September 13, 2024 | 1:00 p.m. – 3:30 p.m. Location: DARS with Virtual Option

In-Person	
Leah Mills, HHR Deputy Secretary	Jason Young, VABIAV
Braden Curtis, DBHDS	Glynis Boyd Hughes, (Proxy for Judy
	Hackler) VALA
Heather Norton, DBHDS	Dana Schrad, VA Chiefs of Police
Aimee Perron Seibert, VCEP	Nicole Durose, dLCV
Trevor Moncure, PSV	Teri Morgan, VBPD
Brian Kelmar, Family Advocate	Christine Schein, VHHA
Jennifer Faison, VACSB	Catherine Harrison, DARS
Karin Addison, Neuro Restorative,	Lisa Jobe- Shields, DMAS
Brain Injury Facility	
Jason Perkins, DMAS	Curt Gleeson, DBHDS
Joshua Myers, Alzheimer's	Lucy Cantrell, Arc of VA
Association of Virginia	
Online	
Delegate Vivian Watts	Tammy Whitlock, DMAS
Steve Ford, VHCA /VCAL	Theresa Champion, VA Autism Project
Martin Mash, VOCAL	Bruce Cruzer, MHV
Elizabeth Hobbs, VA Sheriffs	Kathy Stumm, Family Advocate
Association	
Dana Parsons, Leading Age	Lauren Webb, VACEP
Tonya Milling, ARC of VA	Jonathan Green, OES VA Supreme Court
Byron Wine, The Faison Center	Nathalie Molliet-Ribet, BHC
HF, Family Advocate	Jonathan Gray, Family Advocate

### **MINUTES – Meeting Four**

#### Welcome - HHR Deputy Secretary Leah Mills

Deputy Secretary Mills welcomed and thanked all of the participating workgroup members and members of the public. She reviewed major take aways from the last meeting and key themes discussed to guide recommendations. Deputy Secretary Mills emphasized the importance of continuing to keep the needs identified by individuals with lived experience and their supporters at the center of all decisionmaking.

#### **Public Comment**

No one signed up to provide Public Comment

#### **Stakeholder Perspectives**

#### Families introduced by The Arc of Virginia:

Jonathan Gray shared his family's experiences supporting his adult son who has Autism and Bipolar disorder and is non-verbal with high support needs. Mr. Gray's son received care in state hospitals after being denied admission to private facilities. Mr. Gray shared concerns about the use of restraints during these episodes of care. After receiving care out of state, Mr. Gray's son returned to Virginia and received care in adolescent group homes. Mr. Gray's son was placed under another TDO as an adult and sent to another state psychiatric facility for treatment. While receiving treatment he lost his placement at his group home. His discharge was delayed by the need to find an appropriate placement that would accept him. Mr. Gray recommended the workgroup address the need for more care options for people like his son.

HF shared their family's experience supporting an adult with multiple co-occurring disabilities including developmental disability. They have experienced multiple hospitalizations and periods of homelessness. HF noted that the application process for the developmental disabilities waiver is confusing for families to navigate. HF shared that their family was uncomfortable during the application process having to discuss all support needs and behavioral challenges with the individual present and feared that it may negatively impact their mental health.

#### Family of individual with Traumatic Brain Injury:

Kathy Stumm shared her lived experience supporting her adult brother with traumatic brain injury. Her brother had positive experiences receiving care in assisted living facilities (ALFs). Ms. Stumm shared that her brother had been deemed eligible for a Medicaid waiver but declined because accepting it would have required him to move from his ALF to a group home or skilled nursing facility. His residence at an ALF also limited access to other Medicaid covered services. Ms. Stumm noted 38 states allow ALFs to participate in Home and Community Based Services (HCBS) under Medicaid. She acknowledged that ALFs would have to meet higher requirements but felt that this would be possible for some providers, and she recommended DBHDS and DMAS take steps necessary to expand access to ALFs.

#### Families introduced by Theresa Champion with the Virginia Autism Project:

Ms. Champion provided an introductory presentation to the workgroup. She reviewed core features of Autism Spectrum Disorder (ASD) and DSM-5 levels of severity noting that people with ASD also may have other co-occurring disorders. Ms. Champion noted that ASD is frequently misdiagnosed as mental illness and emphasized the need to identify and provide appropriate supports to people with ASD. She shared common problems encountered by families and individuals with ASD engaging with law enforcement. She concluded by sharing recommendations on behalf of the Virginia Autism Project emphasizing that there is a need for appropriate placements for individuals experiencing a crisis when it is a manifestation of their ASD to receive treatment outside of mental health hospitals.

Sylvia Orli shared a presentation on her family's experience supporting her son through crisis in June 2024 in Arlington, Virginia. Ms. Orli's son has autism and is non-speaking. Ms. Orli said that the family called 911 and REACH. Twelve police officers responded to the 911 call. The family was told that there was a CIT trained officer present but it was unclear which officer it was. Ms. Orli said that REACH did not respond citing police presence, and the crisis center would not accept him due to his Autism. Ms. Orli said that de-escalation was not attempted, and her son was handcuffed and taken to the ER where he was handcuffed to a bed. Ms. Orli's son received sedation in the ER over his objection. Ms. Orli said that her son returned to his normal behavior but continued to be heavily sedated and restrained. He was placed under a TDO while in the ER and his family was not permitted to take him home. Ms. Orli said that the family was not consulted during the decision-making process to place him under a TDO. Her son was allowed to go home after several hours on an IV to treat conditions like severe dehydration he developed there. Ms. Orli presented an alternative narrative of what should have happened. She suggested that one CIT trained officer and one REACH counselor should have to de-escalate and assess. If her son had to be taken from the home he should have been brought to a facility specializing in mental health crisis stabilization for people with neurodevelopmental disabilities, like a crisis center or a psychiatric ER, but must include trained individuals who understand his special needs and can help him without the use of handcuffs or sedation. Ms. Orli said her son should have been released from his ECO and moved from the ER to a quiet room for him to recuperate and staff to assess his crisis level without sedation. Once it was clear that there were no psychiatric placements available and her son was no longer in crisis, his parents should have been permitted to take him home to receive in-home supports.

Peter Francisco shared his experience supporting his adult son with multiple disabilities including Autism and visual impairment through crisis. Three years ago, his son had a crisis consistent with his Autism diagnosis. Mr. Francisco called 911 and requested a CIT trained officer to respond, but the officers who arrived were not CIT trained. Multiple units responded, and his son was handcuffed without de-escalation attempted. Mr. Francisco said that his son deescalated before he was taken from the home, but officers told the parents that he had to either be transported to the ER or he would be arrested for assaulting a law enforcement officer. Mr. Francisco's son was taken to the ER and then placed at a state facility. Mr. Francisco said that his son acquired new challenging behaviors during his time at the facility. When he returned home, he was charged with felony assault of a law enforcement officer. The family hired an attorney

who was successful in getting the charge dropped. Mr. Francisco said other families may not have this experience.

#### Virginia Crisis Connect, Marcus Alert, and the Current Status of the Crisis Services Build-Out - Curt Gleeson and Emilee Grossi, DBHDS

Curt Gleeson provided the workgroup with an overview of the Virginia Crisis Connect (VCC) system. Based on the SAMSHA Crisis Now Model, the VCC system includes Crisis Call Centers, Mobile Crisis, and Crisis Stabilization Sites. Mr. Gleeson noted that REACH is being integrated within the VCC system. He showed stakeholders how they can receive updated information on the status of the build-out on the DBHDS Public Dashboard. Emilee Grossi reviewed the Marcus Alert dispatch levels and triage framework and explained how they support 988 and 911 integration in the areas where Marcus Alert has been implemented. Mr. Gleeson discussed how VCC provides the technological framework for the system coordinating 988 call center operations (launched in January 2022), mobile crisis response (full implementation completed in December 2023), and facility referrals (full implementation projected for January 2025). Mr. Gleeson and Ms. Grossi reviewed how VCC and Marcus Alert operate within Intercept 0 of the Sequential Intercept Model to divert individuals from involvement in the criminal justice system.

#### Workgroup Discussion:

Members asked if data was tracked on the number of people engaging in mobile crisis who have Autism and if mobile response teams are trained to respond to people with Autism. DBHDS staff responded that REACH is integrated with 988 and data is tracked and reported for that program. Developmental disability diagnosis is included in a data template for Marcus Alert going through the process of being approved for implementation. DBHDS does not currently receive this information from private mobile crisis providers who are dispatched through the 988 platform.

DBHDS staff noted that the state is using a data-informed approach to building out the VCC system, accounting for population, TDO rates, etc. The workgroup discussed whether the current REACH infrastructure was adequate to support needs in the state.

Workgroup members asked if individuals can be tracked over time through the VCC system to identify frequent utilizers of crisis services. DBHDS staff noted that the capability exists to view certain case records; however, information sharing across entities is restricted as required by state and federal privacy protections.

Workgroup members suggested building out a mechanism for individuals receiving crisis services and their supporters to submit feedback on the services they received.

#### Reimbursement and Brain Injury Services - Lisa Jobe-Shields and Jason Perkins, DMAS

Ms. Jobe-Shields and Mr. Perkins provided an overview of services covered under current Virginia Medicaid 1915(c) Waivers, which include the Developmental Disability (DD) Waivers

and the Commonwealth Coordinated Care Plus (CCC+) Waiver. They highlighted the crisis supports covered under the DD waivers and noted that the CCC+ waiver does not include skillbuilding and rehabilitative support services. They emphasized that access to a wide array of services is essential to individuals maintaining stability in the least restrictive setting and preventing crisis. They reviewed the requirements of the federal Home and Community Based Settings (HCBS) Rule. They reviewed the current continuum of Mental Health Services under the State Plan noting the new services added to the state plan under Project BRAVO in 2021 and additional changes anticipated under the current Medicaid Behavioral Health Redesign project. They noted that currently there are no residential behavioral health treatment services covered on the state plan for adults, only for youth. They noted that DMAS currently has an 1115 waiver for Substance Use Disorder (SUD) services (ARTS) and a former foster care youth program. DMAS is required to report to the General Assembly annually on plans to develop a parallel waiver for mental health services. They concluded by reviewing the proposed service continuum for Brain Injury. The proposed continuum includes Home and Community Based Services under a 1915(c) waiver and neurobehavioral treatment unit coverage under the state plan for individuals with Brain Injury or neurocognitive disorder, as well as Targeted Case Management coverage under the state plan for individuals with Traumatic Brain Injury (TBI). DMAS was authorized and funded to move forward with the implementation of targeted case management services for individuals with TBL

#### NeuroRestorative's Virginia Programs - Victoria Harding

Dr. Victoria Harding presented to the workgroup on the two programs currently operated by NeruoRestorative in Blacksburg, Virginia. These programs operate on a 24/7 care model that could be replicated and expanded to meet more needs/serve people in the community outside of the institutional setting. These are currently the only programs of their kind serving individuals with brain injury in a community setting in the state to operate with public funding. Funding sources include VA contracts, Discharge Assistance Planning (DAP) funds, workers compensation as well as other states' public funding and commercial payors. Dr. Harding highlighted how states can leverage federal funding through Medicaid Home and Community Based Waivers to support individuals with Brain Injury. She noted there have been over a dozen studies in Virginia evaluating available brain injury resources and gaps in services for individuals with traumatic brain injury and dementia, with all consistently concluding that the needs of individuals and their caretakers are not being met. She referenced acts of the General Assembly in 2022 to require DMAS to establish a Targeted Case Management Service for individuals with severe Traumatic Brain Injury and to convene a workgroup to develop a plan for a neurobehavioral science unit and a waiver program for individuals with brain injury and neurocognitive disorders. She noted that HB1064 was introduced during the 2024 General Assembly Session to create a Brain Injury unit with capacity to treat 575 individuals annually and a fiscal impact of \$10 million. Dr. Harding concluded by emphasizing that a Specialized Neurobehavioral Unit is different from institutional or Nursing Facility settings as they are staffed by Brain Injury Specialists and outcomes-oriented with a focus on increasing independence to support discharge. These units provide highly skilled specialized services for people with challenging behavior and keeps them out of emergency departments, psychiatric hospitals, and the criminal justice system.

### Adjourn

Deputy Secretary Mills provided closing remarks and shared tentative dates for the next meeting.

# **The Reality**

What is really happening as compared to what you are being told by Stakeholders.

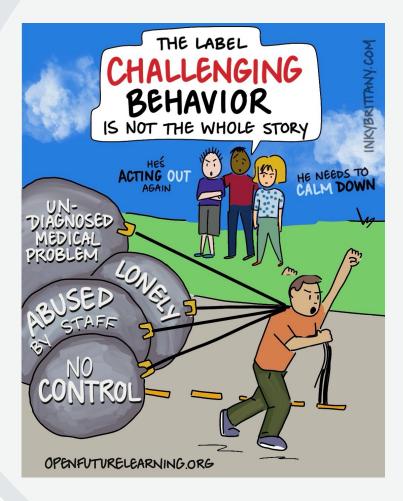
Presentation by Families and Caregivers to SB176/HB888 Workgroup on Placements in Virginia for People with Neurocognitive Disorders and Neurodevelopmental Disabilities



September 13, 2024

# Family & Caregiver Perspective

- Ø About Autism
- Ø About Mental Illness
- Ø Personal Stories When someone calls for help
- Ø Conclusions/Recommendations Where to go when jail and mental health hospitals are not an option



# **About Autism**

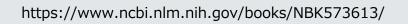
The three core features of ASD are:

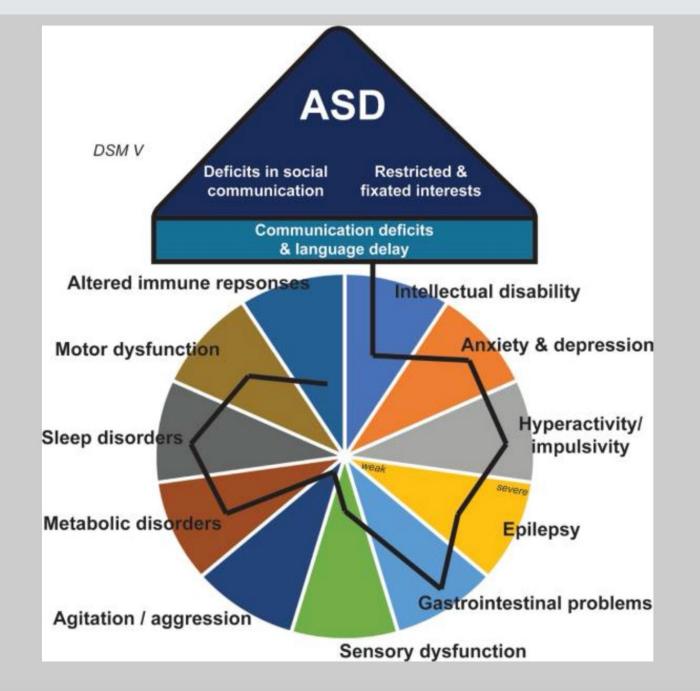
- 1) deficits in social communication,
- 2) restricted and fixated interests together
  - with speech deficits, and
- 3) language delays.

# **Profound Autism and ASD Levels**

- Comorbid symptoms frequently correlated with more severe autism core symptoms.
- Vary from profound, where an autistic person may be non-verbal and unable to function without considerable support,
- To someone needing fewer supports but still having deficits in behavior, communication and perception.
- DSM-5 includes three ASD levels of severity:
  - Level 1 -- requiring support
  - Level 2 -- requiring substantial support
  - Level 3 -- requiring very substantial support

People with ASD also may have other symptoms and comorbidities that vary in severity.





5

# Autism Frequently Misdiagnosed as Mental Illness

### Autism

- Present from birth or appears during early childhood, usually before age 3.
- Lifelong condition. The core symptoms of autism are persistent and consistent.
- No medical cure. Early intensive behavioral interventions can improve skills. Supportive therapies target specific symptoms.

## **Mental Illness**

- Can develop at any age, including childhood, adolescence, or adulthood.
- Symptoms may come and go, cycling between periods of wellness and illness.
   Some mental illnesses involve isolated episodes.
- Often effectively treated with psychiatric medication, psychotherapy, and other interventions with the goal of controlling acute symptoms.

Many autistic traits outwardly resemble behaviors seen in certain mental health conditions. This unfortunately leads to frequent misdiagnosis, especially among verbal children with mild to moderate support needs.

https://jadeaba.org/understanding-autism-vs-mental-illness-diagnosis-differences-and-misconceptions/

# Disproportionate Law Enforcement Response Often Results in Tragic Outcomes

- Many/most autistic individuals are not equipped to handle the direct and aggressive stance of law enforcement during an arrest/investigation.
- People with Disabilities are frequently treated like Enemy Combatants rather than <u>vulnerable people in crisis</u>.
- Ramping up verbal instructions, moving closer or even making physical contact with an autistic individual can quickly backfire/escalate.

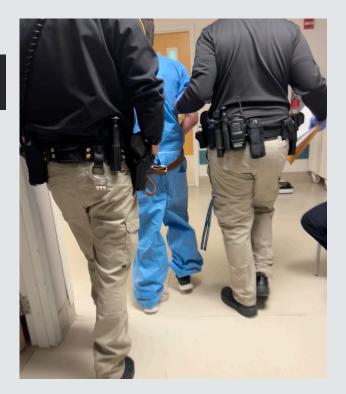
## Disproportionate Law Enforcement Response Often Results in Tragic Outcomes

- Gaze aversion, literal interpretation of language, mutism, reduced reciprocity, and flat affect are frequently interpreted as deceptive.
- Stimming, rocking and pacing are commonly associated with perceptions of dishonest behavior and violations of social conventions which can lead to tragic and deadly consequences.
- Autistic individuals are prone to extreme detachment or fight or flight responses when they cannot manage their environment.
- Demands to answer questions quickly in rapid succession, or the lack of familiar people present to support them in jail and criminal justice system often leads to tragic outcomes.





# Personal Stories



# Parent and Caregiver Accounts of Calling for Assistance

Sylvia Orli

Sandra Jones Judaea Spent Five Days Going From Jail To Hospital To Jail, Mother Complains. What Did It Accomplish Besides Nightmares? -Pete Earley

Yukiko Dove

Anonymous

Pete Fransisco

Farzana Amin

Deborah and Michael Hotaling

# **Conclusions/Recommendations**

- Autism is different You have had experts testify and we have shown that Autistics must be treated & supported differently. Integration into general populations of programs is <u>frequently harmful</u>.
- There is a desperate need for an appropriate and humane placement.
  Alternatives to the current systems that allow an individual to -
  - recover,
  - heal from their trauma,
  - receive needed support and treatment, and
  - then return to their home or to their community as soon as possible.

## ➢ <u>NO</u> TDOs/<u>NO</u> ECOs/<u>NO</u> Jails/<u>NO</u> Mental Health Hospitals.

Comments, Questions or Concerns: tchampion@virginiaautismproject.org





# NeuroRestorative's Virginia Programs

Brain Injury Waivers: Recommendations and Best Practices to Consider

Why Brain Injury Waivers? Creating Capacity in the Community for a highly specialized population



**Challenge:** Individuals with a brain injury diagnosis, particularly those with complex behavioral and health needs do not have access to appropriate long-term settings and services in the community and often have to resort to inappropriate and high-cost institutional and/or out-ofstate placements

**Solution:** Leverage the opportunity to draw down Medicaid federal match to help fund and support existing services and specialized settings for individuals to thrive in their communities

## **Specialized Services & Supports:**

#### **PROGRAMS:**

#### **Inpatient/ Residential:**

- Neurorehabilitation
- Neurobehavioral
- Supported Living (Group Homes & Apts)

#### **In-Home Supports:**

Home & Community Based

#### **Day Programs**

- Structured Day (Center & community based programs)
- Club Houses

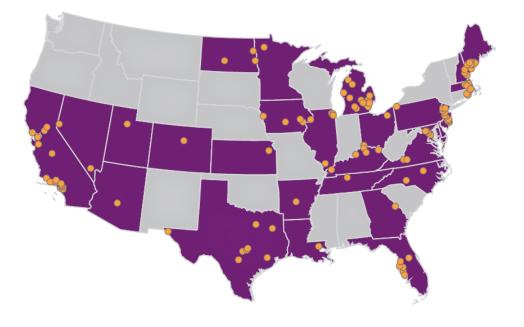
#### **PROVIDING:**

- Physiatry
- Nursing
- Psychiatry
- Neurology
- Neuropsychology
- Physical Therapy
- Occupational Therapy
- Speech-Language Pathology

- Neurobehavioral Analysis & Support
- Life Skills Coaching
- Substance Abuse Counseling/ Services
- Art/ Muisca Therapy
- Personal Fitness
- Case management
- Vocational Skill Development

## State Waiver Experience: Common Components & Goals





### Consider:

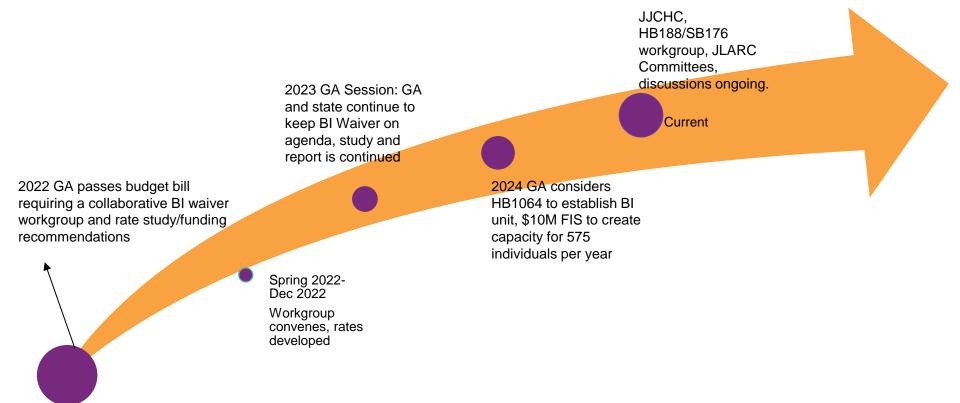
- Tiers/ levels of care tied to needs
- Efficient qualifying, referral and admissions process
- Transition from institutions to the community for specialized residential treatment

- Programs in 28 states and growing
- CMS encourages flexibility, similar to other Home and Community Based Waivers: can be as narrow or as robust to fit the needs of each state
- Must prove budget neutrality
- Residential/ facility-based component for individuals who present with high acuity support needs

### Virginia's BI Waiver Journey To Date



- There have been a total of sixteen (17) studies to evaluate available BI resources and gaps in services for individuals with TBI and dementia in Virginia
- Findings have been consistent in concluding that we are not meeting the current needs of BI individuals and their caretakers



### Blacksburg, Virginia Programs: 26 beds (14 + 12)





- 24/7 care model that can be replicated and expanded to meet more needs/serve people in the community outside of the institutional setting (currently only 2 exist in VA)
- Dedicated MDs, NPs, Psychs, OTs, RNs and other staff as FTEs who specialize in serving the BI population in community settings
- Only site in the state to serve the identified population with public funding (discharge from state psych hospital, other public funds)
- Serves Veterans through VA contract and others through DAP, workers comp, commercial and other states' public funding



## **Brain Injury Specialized Setting**



How is a Specialized Neurobehavioral Unit different from institutional or Nursing Facility settings?

- · Focus on increasing safety, independence and quality of life
- Outcomes oriented
- Discharge planning begins prior to admission
- · Skills learned and practiced in a home environment and in the real world of the community to prepare for discharge back home
- May require skilled nursing care, typically not 24/7 medical care needs, though available
- · Generalization of skills throughout a highly scheduled day for maximum practice and skill
- Lowest level of staffing is 1:3 (not inclusive of clinical staff) and is often 1:1
- All staff are certified in Professional Crisis Management, many are Certified Brain Injury Specialists and all complete competency based training together with medical req's
- Direct Family Training is essential
- Specialization (CARF Accredited as a Brain Injury Specialty Program)
- · Part of a continuum that safely improves independence reduces services over time
- · Individualized, person-centered model to increase community reintegration
- Licensed by the State of Virginia as a Provider of Brain Injury Rehabilitation.

Critical for Virginia because...

- Provides a highly skilled specialized services for people with challenging behavior
- Keeps people out of psych hospitals, avoid emergency departments and justice systems
- Creates a setting to bring people home from out of state placements

### Looking Ahead ...



# Opportunities of Innovation, Cost Savings and Quality

# **Our Experience**

A Mental Health Crisis with a non-speaking neurodevelopmentally disabled individual in Arlington, Virginia

June 2024

### Thursday June 20, 1 AM.

BJO is agitated and destructive at home in the middle of the night. Parents call 911 and REACH for help.

- What happened: In response to our 911 call, 12 police come to the house. There is a CIT trained officer but it is not clear who that is. REACH refuses to get involved "because the police are there". The police surround BJO, hold him down and handcuff him. No attempt at de-escalation is made. BJO is terrified and fighting. They take him to an ER.
- What should happen: one CIT trained officer and one REACH counselor come to the house to assist in de-escalating the situation and assessing what needs BJO has at that moment. Situation is defused and REACH comes to the home the next day to update a safety plan.

### Thursday June 20, 1:30AM.

BJO is brought to the ER and put under an ECO

- What happened: BJO is brought to the ER in handcuffs by police. The ER is noisy and extremely overwhelming. He is scared and completely dysregulated. He is forcibly handcuffed to a bed, and knocks his father down in the process. Father breaks his elbow. After several hours of BJO screaming in terror and pain, he is sedated to keep him quiet.
- What should happen: BJO is brought to a facility specializing in mental health crisis stabilization for people with neurodevelopmental disabilities. This can be a Crisis Intervention Center or a psychiatric ER, but must include trained individuals who understand these special needs and can help BJO without the use of handcuffs or sedation.

### Thursday, June 20, afternoon.

BJO is released from ECO but kept at ER to wait for a psychiatric hospital placement

- What happened: BJO is released from the handcuffs but kept under sedation to keep him quiet. When he awakes from sedation, he is given another dose. At one point, the nurse comes at him with a sedation pill, and he refuses. The guard tries to hold him down, and he fights to escape. Many police, hospital staff and guards enter the space, and BJO panics and kicks, spits and bites in a fight-or-flight response. BJO is sedated and branded as dangerous and aggressive.
- What should happen: BJO is released from the ECO, and is moved from the ER to a quiet room for him to recuperate, and to staff to assess his crisis level. No sedation is forced on him.

### Friday June 21, 10AM.

BJO is placed under a TDO in the ER

- What happened: Seeing that no psychiatric placement will be available any time soon, parents are ready to take BJO home from ER. BJO is calm and acting normally. But, because of the aggressive incident the day before, DHS puts BJO under a TDO. He is put in handcuffs (arms and legs) and sedated heavily. BJO refuses to eat or drink.
- What should happen: Seeing that no psychiatric placement will be available any time soon and BJO is no longer in crisis, parents discuss the matter with the DHS, hospital and police, and agree to take BJO home, where he will receive in-home supports.

### Saturday June 22, 2PM.

**BJO goes into medical distress** 

- What happened: After 60 hours of constant sedation, and very little food or drink, BJO develops severe dehydration and rhabdomylosis. The hospital overrides the TDO but keeps BJO in ER to treat his serious condition. He goes home after several hours on an IV. DHS is furious at hospital for releasing BJO.
- What should happen: None of this! See previous slides.

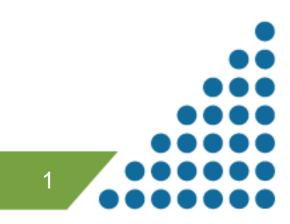
NOT OKAY!



## Crisis Service Buildout, Marcus Alert, and Virginia Crisis Connect September 13, 2023

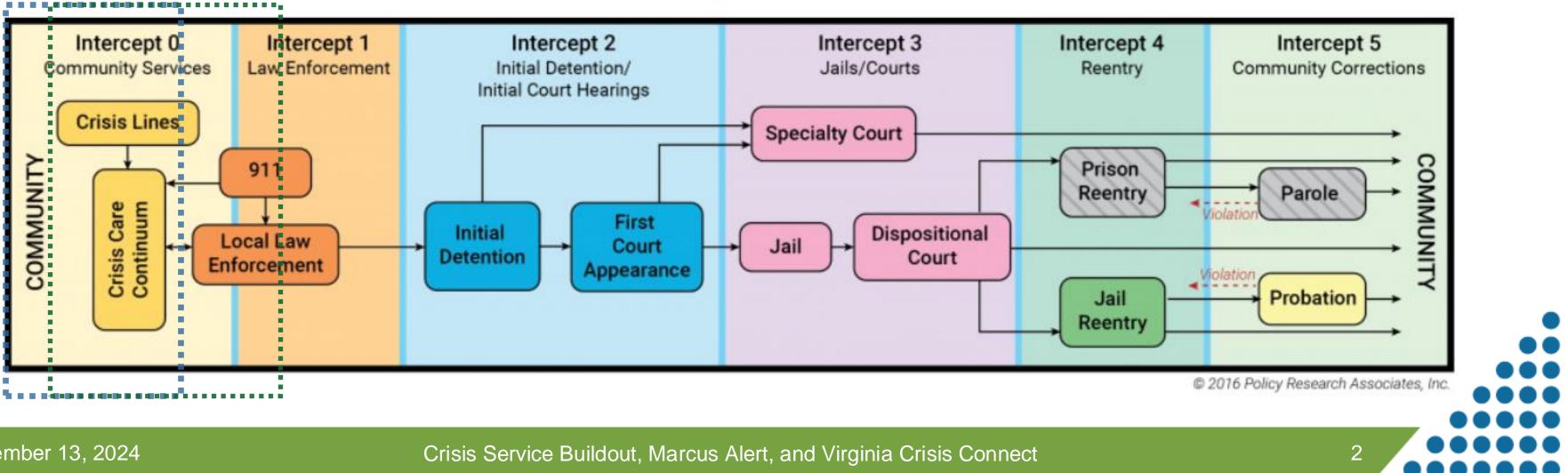
Curt Gleeson, Assistant Commissioner, Crisis Services Emilee Grossi, Marcus Alert Coordinator





**Right Help. Right Now.** Workstream 1 of Governor Youngkin's plan to transform behavioral health care focuses on development and implementation of the Crisis Now continuum across Virginia.

**Marcus Alert** is at the intersection of Intercepts 0 and 1, seeking to divert individuals needing behavioral health care from the criminal justice system



**Sequential Intercept Model** 

# Right Help. Right Now. Workstream One

# Ensuring Same-day Care for Individuals Experiencing **Behavioral Health Crisis**

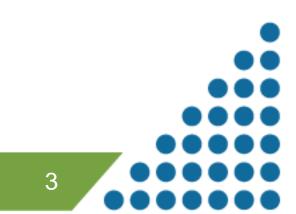


**Transforming Behavioral Health Care for Virginians** 

Crisis Service Buildout, Marcus Alert, and Virginia Crisis Connect

September 13, 2024





## Someone to Call

### **Crisis Call Centers**

0

When someone calls **988**, a trained crisis worker will provide support such as safety planning, referrals, and a listening ear. If needed, crisis workers can connect to the full continuum of services. Through Virginia's coresponder initiative (Marcus Alert), appropriate calls to 911 can be routed to the 988 call centers.

## Someone to Respond



### **Mobile Crisis**

Mobile Crisis Response teams are deployed in real-time, 24 hours a day, to the location of the individual experiencing a behavioral health crisis. These rapid responders provide onscene evaluation, intervention, and connection to follow-up resources.

Crisis Now in Virginia

## Somewhere to Go



### **Crisis Stabilization Sites**

23-hour Crisis Receiving **Centers** and short-term residential **Crisis Stabilization Units** provide a safe, secure communitybased environment for assessment, resources, and emergent crisis treatment.



### **Crisis Receiving Centers:**

- Service provided for up to 23-hours
- Non-residential, site-based
- Recliners, not beds
- Walk in or police drop off; no wrong door entry

### **Core services include:**

- Clinical needs assessment
- Access to peer services
- Psychiatric evaluation & medical assessment
- Care coordination

### **Crisis Stabilization Units**

- Service provided typically for 3-5 days Residential
- Consumers are admitted based on screening

### **Core services include:**

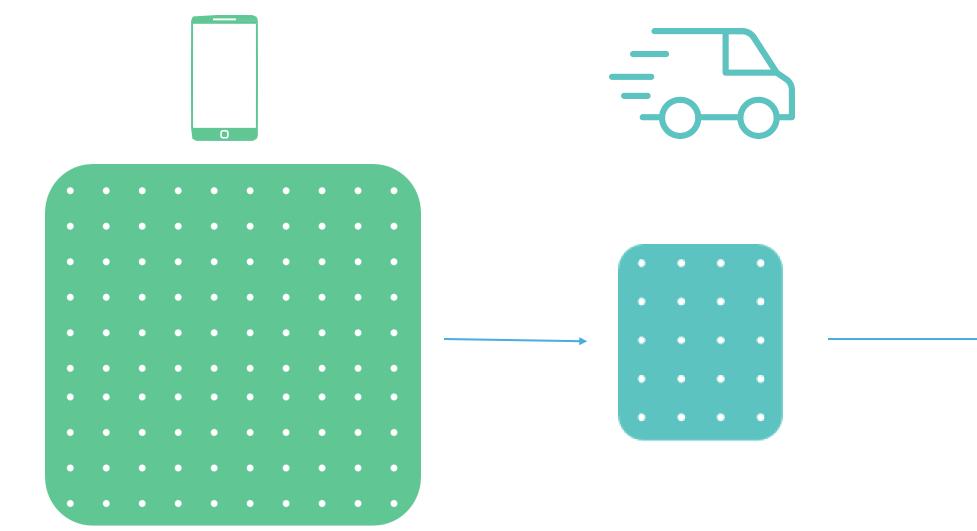
- All services provided at CRC, and Crisis intervention • Treatment planning Individual and group therapy

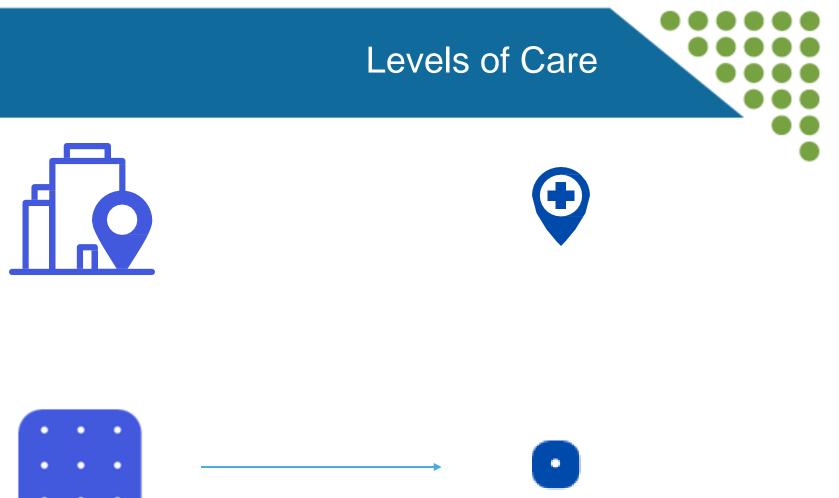
### **Comprehensive Psychiatric Emergency Programs (CPEPs):**

• Based out of private hospital Emergency Departments, CPEPs are safe environments where psychiatric assessments and initial intervention can be provided for individuals with significant medical comorbidities or exceptional risk profiles.

Crisis Service Buildout, Marcus Alert, and Virginia Crisis Connect

### Crisis Site Comparison





If **100** people call 988, 80 of those calls can be resolved over the phone.

Mobile crisis response can be dispatched for the remaining **20**.

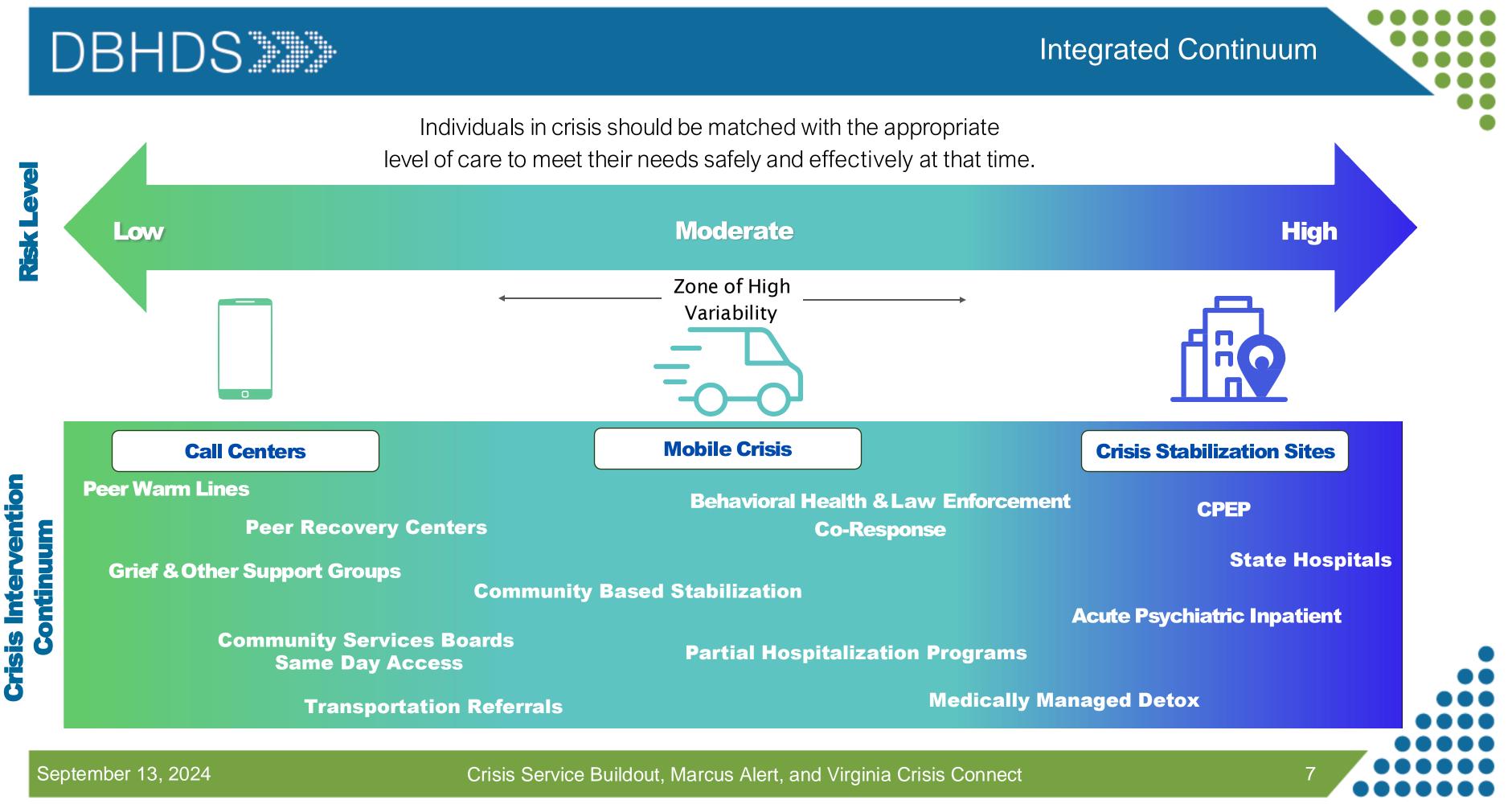
Of those 20, nine may need further treatment at a Crisis Stabilization Site.

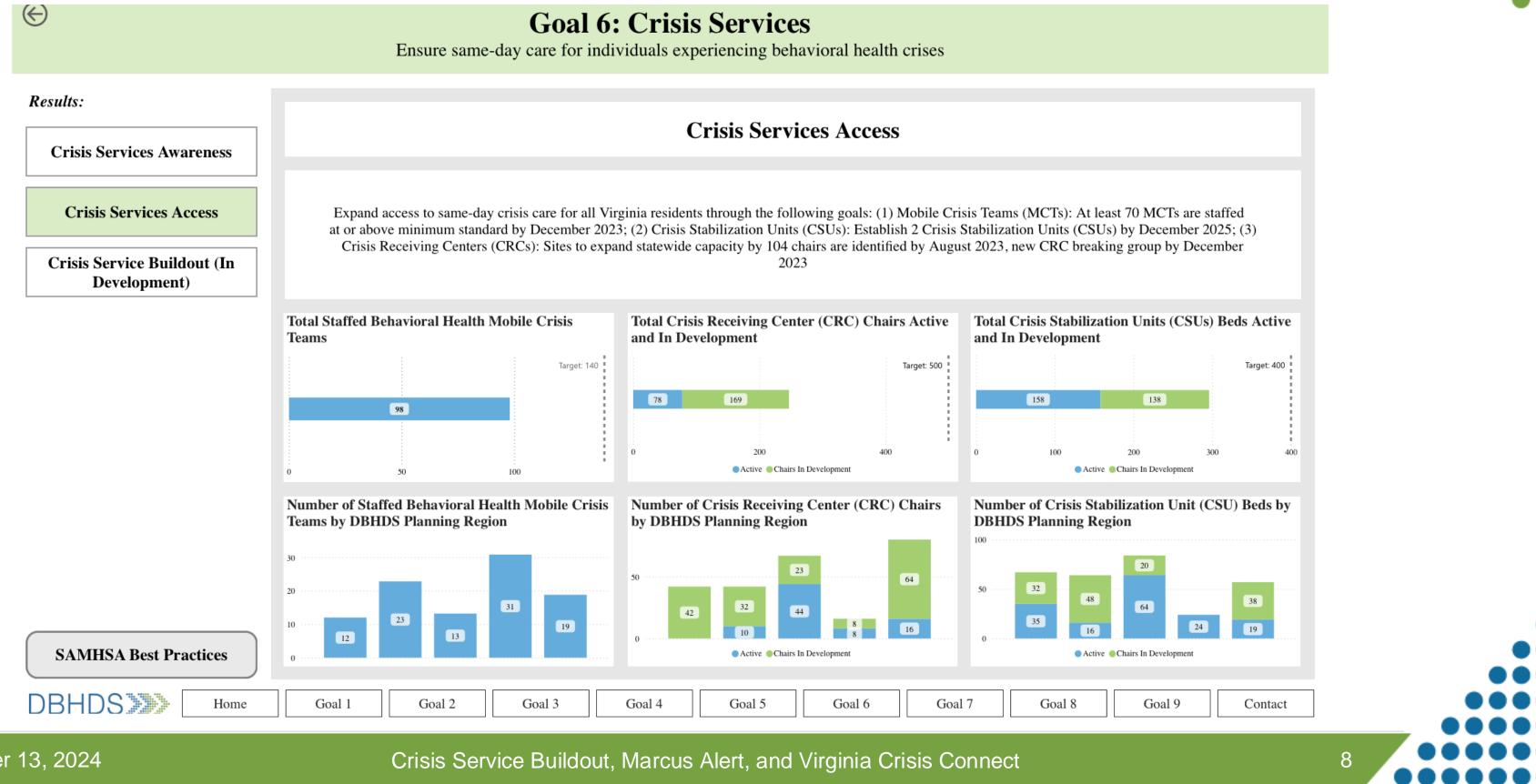
### **Out of those nine, one**

may require services at a higher level of care, like a hospital, while the other eight return safely to the community.

6

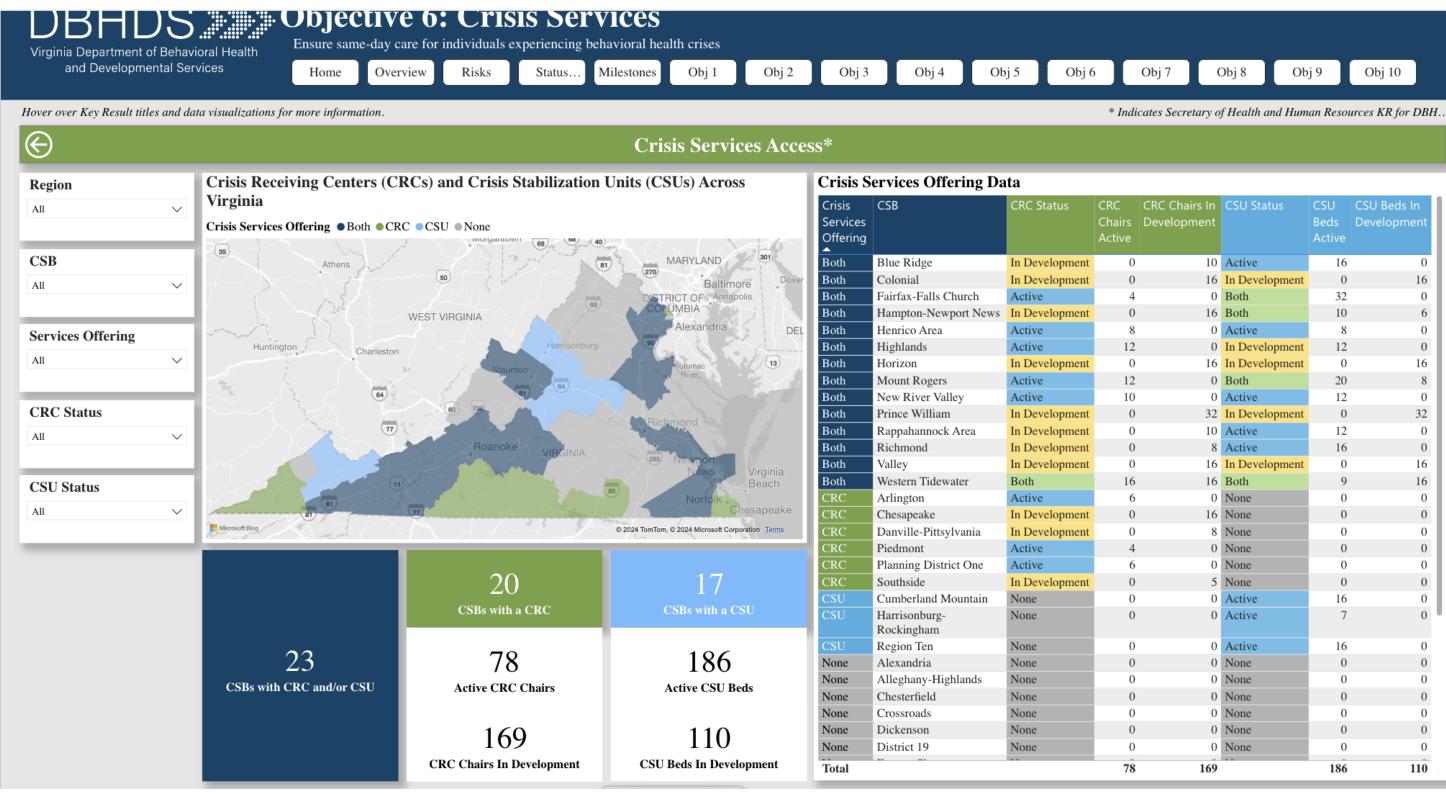






September 13, 2024

### **Public Dashboard**



September 13, 2024

Crisis Service Buildout, Marcus Alert, and Virginia Crisis Connect

### **Public Dashboard**

2	Data	

g Da	la					
	CRC Status	CRC Chairs Active	CRC Chairs In Development	CSU Status	CSU Beds Active	CSU Beds In Development
	In Development	0	10	Active	16	0
	In Development	0		In Development	0	16
h	Active	4	0	Both	32	0
News	In Development	0	16	Both	10	6
	Active	8	0	Active	8	0
	Active	12	0	In Development	12	0
	In Development	0	16	In Development	0	16
	Active	12	0	Both	20	8
	Active	10	0	Active	12	0
	In Development	0	32	In Development	0	32
l I	In Development	0	10	Active	12	0
	In Development	0	8	Active	16	0
	In Development	0	16	In Development	0	16
	Both	16	16	Both	9	16
	Active	6	0	None	0	0
	In Development	0	16	None	0	0
a	In Development	0	8	None	0	0
	Active	4	0	None	0	0
ne	Active	6	0	None	0	0
	In Development	0	5	None	0	0
ain	None	0	0	Active	16	0
	None	0	0	Active	7	0
	None	0	0	Active	16	0
	None	0	0	None	0	0
is	None	0	0	None	0	0
	None	0	0	None	0	0
	None	0	0	None	0	0
	None	0	0	None	0	0
	None	0	0	None	0	0
	••	78	169	••	186	110

9

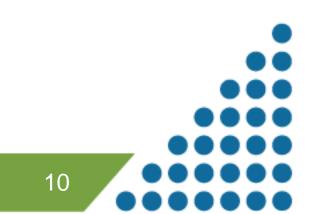


# The Marcus-David Peters Act

September 13, 2024

Crisis Service Buildout, Marcus Alert, and Virginia Crisis Connect

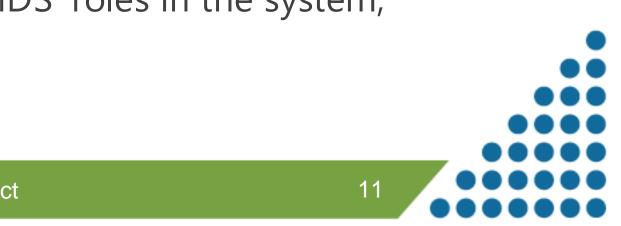






- Requires the development of a comprehensive crisis response system, including community care teams, and three protocols for specialized response to behavioral health emergencies
- Seeks to prevent individuals' involvement in the criminal justice system as a result of seeking help for behavioral health emergencies
- Aims to reduce unnecessary involvement of law enforcement during behavioral health emergencies
- Emphasizes the importance of creating a recovery-oriented, health- and equity-focused crisis response system
- See § 9.1-193 and § 37.2-311.1 for more details about DCJS' and DBHDS' roles in the system, respectively





Protocol #1 details diversion of calls from 911 to 988

- The state plan requires all Level 1 calls to be fully diverted.
- The state plan allows for collaboration between 911 and 988 for Levels 2-4. •
- Response types for calls identified as Levels 2-3 are determined by stakeholders within the communities.

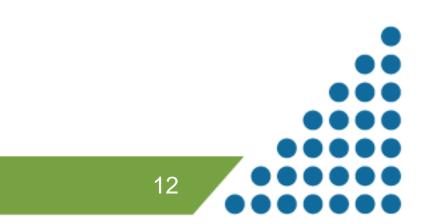
Protocol #2 details LE backup for MCTs

• Each locality must formalize agreements with all stakeholders who operate under the Marcus Alert framework.

Protocol #3 details specialized LE response to behavioral health emergencies

• Since behavioral health crises can present with emergent safety concerns, LE will continue to interact with individuals experiencing behavioral health crises. Policies require extensive behavioral health training and revision of LE policies and procedures.



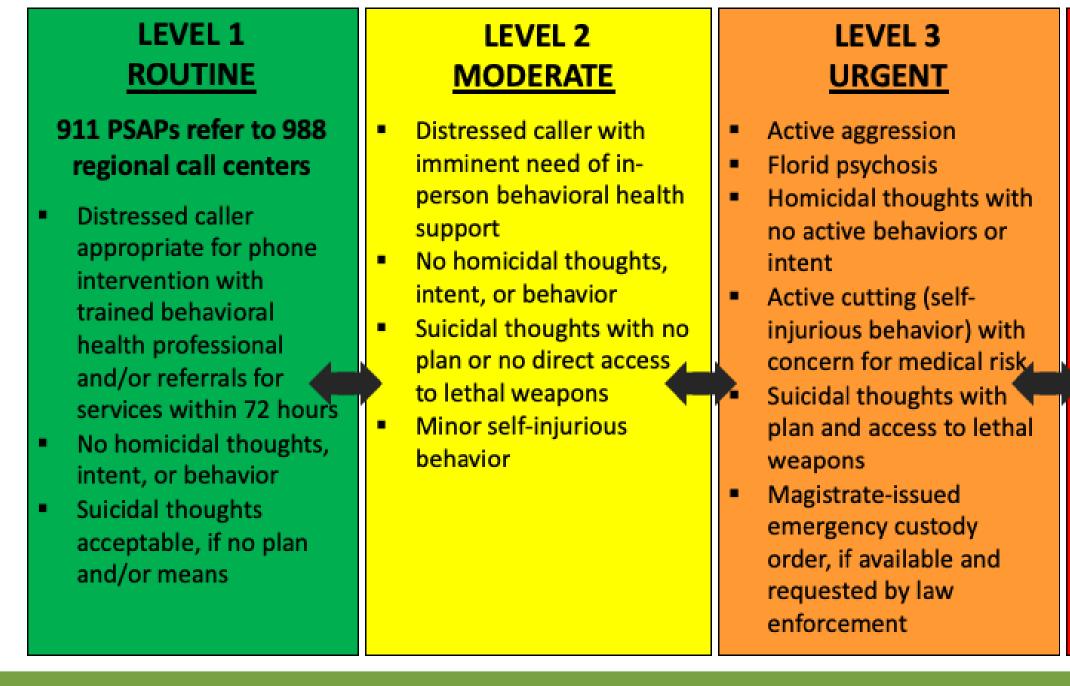




### INVOLVE BEHAVIORAL HEALTH AS SOON AS POSSIBLE

### BEHAVIORAL HEALTH REMOTE ENGAGEMENT DURING TRANSIT IF POSSIBLE

### ASSESS NEED FOR MEDICAL RESPONSE



September 13, 2024

Crisis Service Buildout, Marcus Alert, and Virginia Crisis Connect

## Marcus Alert Dispatch Levels

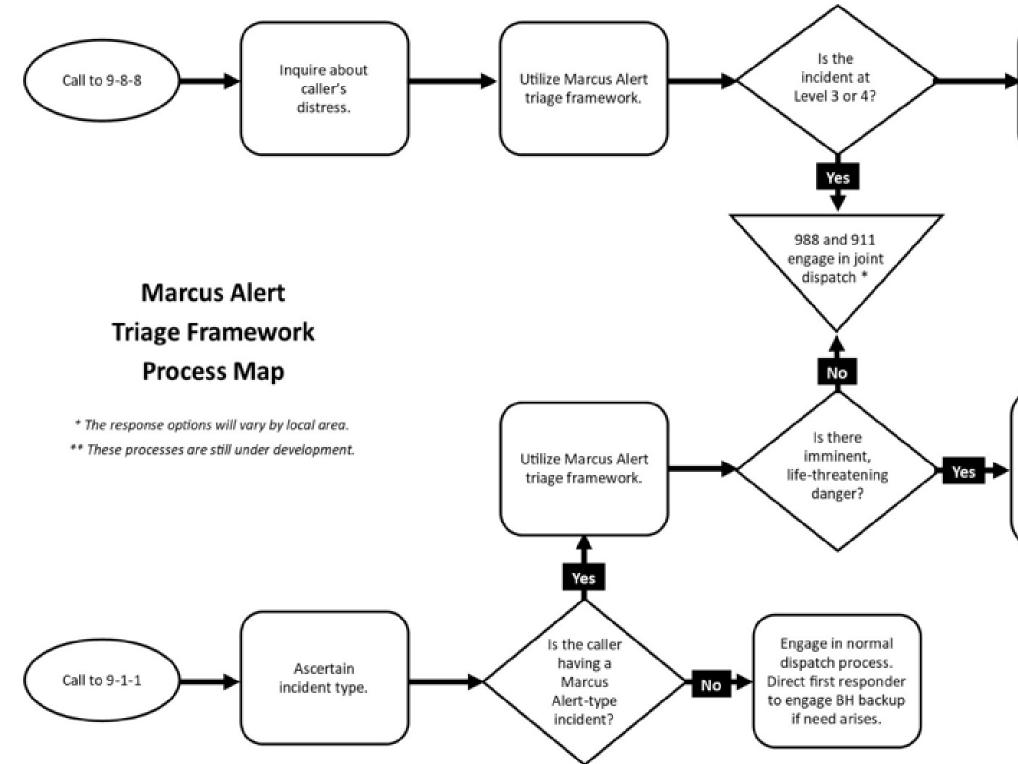
### LEVEL 4 EMERGENT

### 911 PSAPs dispatch law enforcement, EMS, and/or fire without delay

- Direct, immediate threats to life
- Active suicide attempt
- Active assault on others with ability to cause significant harm
- Any gun present and accessible
- Magistrate-issued emergency custody order issued with immediate security threat

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September 13, 2024

Crisis Service Buildout, Marcus Alert, and Virginia Crisis Connect



Continue 988 call center procedures and response.\*\*

**Dispatch first** responders as soon as possible. Send CITtrained first responders, if available. Engage BH remotely during transit, if possible.

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## **Implemented Areas**

- **Encompass CSB** •
- Prince Williams CSB
- Highlands CSB
- **Richmond BHA** •
- Virginia Beach CSB
- Rappahannock Area CSB
- Fairfax CSB •
- Blue Ridge Behavioral Health •
- Chesterfield County CSB •
- Hampton-Newport News CSB
- Horizon Behavioral Health
- Loudoun County CSB
- New River Valley CSB
- Henrico BHA •
- Wester Tidewater CSB
- Arlington CSB
- Alexandria CSB

- and resources.
- Crisis Continuum.



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• Each jurisdiction has developed their own form of community cares team based on community need

• These community care teams are the most common entry point to the services developed in Virginia's



# Virginia Crisis Connect

September 13, 2024

Crisis Service Buildout, Marcus Alert, and Virginia Crisis Connect







Virginia Crisis Connect (VCC) is the state funded web platform and infrastructure facilitating service delivery and integration across the crisis continuum.



When a caller dials 988, the VCC functions like a Public Safety Answering Point (PSAP) logging call times, duration, and outcomes, and facilitating other critical connections.

### **System Benefits:**

- Provides appropriate oversight for regional and statewide crisis operations to ensure resources are strategically deployed.
- Facilitates risk assessments using nationallyrecognized evidenced-based content.
- Provides broad resource library for call center staff, and allows for referral, scheduling, and follow-up contact.
- Provides a unified data platform for all crisis operations in the Commonwealth, allowing for datadriven decisions at multiple levels.

Launched in January 2022

# Mobile Crisis Response

Sophisticated dispatch functionality that deploys public and private mobile crisis responders and tracks response times and outcomes

### System Benefits:

- Uses GPS location of provider and individual to minimize response times.
- Logs multiple data points across service delivery,
- Provides connection between mobile crisis providers, dispatchers, and first responders, ensuring safety of providers and individuals.
  - Connects hub managers, outpatient providers, and other resources with providers, improving outcomes.

Full implementation December 2023

## Virginia Crisis Connect

## Facility Referral Module

Improving on the previous bed registry, VCC will facilitate real-time document sharing; waitlist information; and accurate, up-todate, psychiatric bed availability.

### **System Benefits**:

- System-wide transparency of real-time bed availability facilitates patient placement, reducing state waitlist utilization.
- Provides digital information sharing between CSB and hospital admissions staff, eliminating the burden of faxing and phone calls.
  - IT integration with hospital bed management systems reduces administrative burden for hospital staff.



Full Implementation by January 2025





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

Secretary of Health and Human Resources Friday, October 11, 2024 | 10:00 a.m. – 12:30 p.m. Location: DARS with Virtual Option

Sharon Nannar Alzhaimar's Association		
Sharon Napper, Alzheimer's Association		
Catherine Harrison, DARS		
Trevor Moncure, PSV		
Byron Wine, The Faison Center		
Karin Addison, Neuro Restorative		
Brian Kelmar, Family Advocate		
Dan Reeves, Community Brain Injury		
Services		
Nicole Durose, DLCV		
Teri Morgan, VBPD		
Josh Myers, Alzheimer's Association of		
Virginia		
Dana Schrad, VA Chiefs of Police		
Heather Orrock, VOCAL Virginia		
Jonathan Green, OES		
Tonya Milling, The Arc of Virginia		
Nathalie Molliet-Ribet, BHC		
Joran Sequeira, Virginia College of		
Emergency Physicians		

### **DRAFT MINUTES – Meeting Five**

Welcome – HHR Deputy Secretary Leah Mills

Deputy Secretary Mills offered the opportunity for Delegate Watts and Senator Favola to provide comments before starting the meeting. Deputy Secretary Mills welcomed and thanked all the participating workgroup members and members of the public.

#### **Public Comment**

No one signed up to provide Public Comment

#### **Stakeholder Perspectives**

#### Perspectives from Families, Virginia Autism Project:

Ms. Theresa Champion provided a summary of Virginia Autism Project's response to the draft recommendations presented to the workgroup. She emphasized that individuals with Autism Spectrum Disorder (ASD) may not respond to standard treatments for behavioral healthcare and that the recommendations should incorporate specialized models of care for this population. Ms. Champion also shared concerns that the proposed sole manifestation criteria would not be successfully implemented with current prescreener qualification requirements and assessment tools utilized during evaluations and suggested that they be changed. She highlighted issues with the REACH program as discussed previously by the workgroup and advocated for a new pilot program to address the needs of this population. Ms. Champion also noted that continued research and analysis would be needed to support implementation of the recommendations. Deputy Secretary Mills invited Virginia Autism Project to submit a written summary of their comments.

#### Perspectives from Families, Virginia Alzheimer's Association:

Ms. Sharon Napper, a community partner who does statewide law enforcement training, provided a presentation to the workgroup. She reviewed statistics on the prevalence of Alzheimer's and impacts on caregivers. Ms. Napper emphasized the need for enhancing training for law enforcement through community partnerships to improve their ability to identify and engage with individuals with neurocognitive disorders. Community partnerships can also include engagement with local high schools and colleges to increase knowledge among the general population on best practices for engaging with and supporting people with neurocognitive and neurodevelopmental disorders.

#### Law Enforcement Perspective, Virginia Association of Chiefs of Police:

Ms. Dana Schrad shared perspectives from law enforcement officers (LEO) on their role in responding to mental health crises. She emphasized that LEOs are not trained mental health providers, but rather are trained to assess current and imminent risks and prevent harm. Ms. Schrad noted that there are limited options available for LEOs responding to a mental health crisis. Officers may choose not to act if they determine there is no imminent danger, pursue an ECO/TDO, or make an arrest as a last resort. Ms. Schrad corroborated points made during prior workgroup discussion noting that a lack of options has created an overreliance on law enforcement to respond to mental health crises. She also acknowledged that there is a larger systemic issue with LEO workforce shortages which have led to an increase in newer officers in the workforce who generally have less communication experience. Ms. Schrad concluded by stating that law enforcement agencies remain compassionate and committed to serving these populations, but they are best used as a last resort call when all other options have failed.

#### **REACH Overview-** Heather Norton, DBHDS

Ms. Norton provided a presentation on the REACH program. REACH is a best practice model operated in Virginia through five regional hubs. REACH services are available to anyone with a developmental disability diagnosis, they do not have to be waiver-eligible. REACH is available 24/7 and can now be accessed by calling 988. A common challenge is ensuring that REACH is called at the right time. If an individual is too far into a crisis, it is difficult for the REACH program to be responsive and helpful. If called too early, then the individual's crisis is not severe enough to warrant a REACH response. Ms. Norton recognized that there is a need to refine the REACH process.

#### Workgroup Discussion:

Nicole Durose, representing the DisAbility Law Center of Virginia, shared concerns that she is consistently receiving the same messages from family members regarding their inability to access REACH services. She requested more information on how DBHDS is addressing these concerns.

Ms. Norton noted that because REACH is regionally based there is variation across programs with some challenges that are unique to each region arising from a range of factors. Data collected by DBHDS indicates that while the REACH program is not working for some individuals it is working for others. She agreed that DBHDS can work to improve communication with impacted stakeholders.

Family advocate, Brian Kelmar, agreed that law enforcement should not be the one to close that gap when REACH does not respond and asked what an interim process should be implemented to address this issue.

#### **Review Draft Recommendations and Group Discussion**

The workgroup reviewed and discussed the draft recommendations. Discussion focused on issues associated with individuals with neurodevelopmental disabilities and neurocognitive disorders being placed in state facilities that do not have the expertise and staffing to adequately meet their specialized needs and the potential consequences of amending the code to prevent these placements when no alternative services are available. Members discussed the timeline for the workgroup recommendations to move forward and options for continued collaboration on long term solutions. They also noted the need to include those who are criminal justice involved, caregivers, and potential housing partners in outgoing communications from the workgroup.

#### Adjourn

Deputy Secretary Mills provided closing remarks and shared the next steps for finalizing workgroup recommendations. She noted that staff would work to incorporate changes discussed during the meeting and send an updated draft for the workgroup to review and comment on. Deputy Secretary Mills concluded by highlighting that on October 31, 2024, the Secretary will be presenting an update on the workgroup to the Joint Health and Human Services Sub-Committee.