

disABILITY LAW CENTER

OF VIRGINIA



Protection & Advocacy for Virginians with Disabilities

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April 21, 2016

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Dr. Jack Barber, Interim Commissioner
Department of Behavioral Health and Developmental Services
P.O. Box 1797
Richmond, VA 23218-1797

Dear Dr. Barber,

The disAbility Law Center of Virginia is deeply concerned about the inadequate array of services available to individuals with complex needs and with the lack of accountability of those serving them. As the Interim Commissioner, you are the person best positioned to lead DBHDS and the CSBs in effecting systemic change and increasing accountability.

Attached is a draft of dLCV's report regarding the failure to provide appropriate services for Brittany resulting in her unnecessary institutionalization. In the past two weeks, a previously agreed upon plan has been discarded. New testing and a change in diagnosis did not change the individual but totally changed her access to services and providers overnight. Providers at Hampton-Newport News CSB, REACH (region V), Eastern State Hospital and at DBHDS are aware of Brittany's needs, yet fail to meet those needs. Brittany continues to suffer from the state's inability to appropriately support her.

dLCV is seeking your thoughtful leadership to ensure that Brittany is promptly discharged into the community with appropriate services and supports. dLCV is considering making this report available to the public. We welcome your response by May 2, 2016.

Sincerely,

A handwritten signature in cursive script that reads "Kara McCallum". The signature is written in black ink and includes a long horizontal flourish extending to the right.

Kara McCallum
Disability Rights Advocate

Cc: Mr. Frank Gallagher, Eastern State Hospital Facility Director
Ms. Natale Ward, Hampton-Newport News CSB Executive Director

This is a story about a 22 year old woman named Brittany. She has both an intellectual disability and bipolar disorder¹, which is sometimes referred to as being *dually diagnosed*. She has had 40 residential placements² since 2012 – many of those in institutions where she has been subjected to sexual assault, physical assault, neglect, and inappropriate seclusion and restraint. She is currently committed to Eastern State Hospital, even though professionals agree she does not need to be there. State-funded programs have failed to coordinate services, at times leaving Brittany homeless and without needed medications. Providers hired to support, care for, and assist Brittany in her recovery have charged her with crimes, often for behaviors that are part of her diagnosed disabilities. Providers, however, are rarely held accountable for the abuse and neglect of Brittany while in their care. Brittany wants this chaotic cycle to end. She wants a safe, stable home with adequate services and supports.

Background:

The Commonwealth has a long history of favoring institutional care over comprehensive community based services for individuals with complex support needs. Virginia entered into a settlement agreement with the United States Department of Justice (US DOJ) in 2012 after an extensive investigation revealed the state's intellectual and developmental disabilities (I/DD) service system was not compliant with federal law³. The US DOJ cited the Commonwealth's service system for failing to provide services to individuals with I/DD in the most integrated setting appropriate to their needs. Virginia has since agreed "to prevent the unnecessary institutionalization of individuals with ID/DD... (and to) develop and provide the community services"⁴ to come into compliance with federal law.

Virginia agreed to develop statewide crisis services for individuals with I/DD by June 30, 2012 as one component of the Commonwealth's settlement agreement with the US DOJ. An expert reviewing the progress of the settlement agreement stated "crisis services are a cornerstone in a community-based services system that prevents the unnecessary institutionalization of individuals with ID/DD."⁵ The agreement provides that crisis services will support individuals who are experiencing both behavioral and psychiatric crises. Services are to be mobile and include crisis prevention both at home and in the community. The crisis system is to include collaboration with other systems, such as law enforcement, to avoid institutional placements. Law enforcement was included with the intention of diverting people from the criminal justice system, in part, to reduce criminalization of behaviors that are manifestations of disabilities. The settlement agreement also calls for the system to provide crisis stabilization and respite as an alternative to institutionalization. Virginia's crisis system has failed to fully meet the needs of all individuals with I/DD, particularly those who are dually diagnosed.⁶

As the designated protection and advocacy system for people with disabilities, dLCV is monitoring the Commonwealth's implementation of the settlement agreement. The dLCV routinely works with individuals with a variety of disabilities, including those with I/DD and mental illness. Our work has revealed some progress and many deficiencies in Virginia's developing service system for individuals with dual diagnoses. The following story illustrates the harm done by the Commonwealth's failure to fully comply with the settlement agreement.

Brittany's Childhood:

As a young girl, Brittany dreamed of becoming a doctor so she could help people.⁷ However, even at a young age she had experienced many uncertainties in her unstable home life. Brittany's mother struggled with substance abuse and was unable to provide a secure environment. By age three, Brittany reports that her grandparents were her primary caretakers. Brittany longed to be with her mother and at times acted out in frustration. She had multiple school suspensions for fighting and was eventually expelled and placed on homebound instruction in second grade.⁸ While still in elementary school, Brittany was subjected to her first psychiatric hospitalization. Throughout Brittany's childhood, her mother was in and out of her life. At age 11, Brittany remembers being raped by her mother's boyfriend. The trauma Brittany experienced affected her greatly, resulting in intense anxiety and a lasting fear of men. Brittany states that her last year of school was eighth grade. At this point, she remembers being bounced around from the Department of Juvenile Justice, foster care, and residential treatment facilities. Many service systems interfaced with Brittany and her family and developed plans for her. These have included the local Community Services Board, Department of Social Services, and Department of Education along with the state Department of Juvenile Justice and Department of Behavioral Health and Developmental Services. However, the state and local systems have repeatedly failed to adequately provide supports to Brittany and her family.

Harm since the Settlement Agreement:

By the time she was a young adult, Brittany had already resided in multiple psychiatric hospitals, residential programs, detention centers, and foster homes. In fact, since the settlement agreement was reached in 2012, she has cycled in and out of group homes, psychiatric hospitals, and correctional facilities 40 times⁹ - typically transitioning from one location to another during a period of crisis. The formal crisis system has had a consistent presence in Brittany's life; however, it, coupled with community providers, has not provided Brittany with effective intervention to prevent institutionalization. Hampton-Newport News Community Service Board (H-NN CSB) is the entity responsible for providing case management or support coordination to Brittany. H-NN CSB is responsible for obtaining appropriate services for people in the community through a performance contract with the Department of Behavioral Health and Developmental Services (DBHDS). Inadequate crisis services and case coordination have left Brittany homeless, without medication, and without necessary supports in the community.

The system's failures have led Brittany to institutional care which has repeatedly traumatized and re-traumatized Brittany. This institutional care has contributed to Brittany being sexually assaulted, physically and verbally abused, and neglected by staff and peers. Hospitals have subjected Brittany to mechanical restraint, physical restraint, and seclusion dozens of times. Experts state that seclusion, in particular, is contraindicated for individuals with histories of self-injury like Brittany. Even though contraindicated, Eastern State Hospital (ESH) repeatedly secluded Brittany. She attempted to strangle herself in a seclusion room in October 2014.¹⁰ Even after this attempt, ESH continued to put Brittany in seclusion. Other

hospitals have also repeatedly restrained Brittany, even though victims of sexual trauma can be re-traumatized when physically and mechanically restrained by staff.

"The social worker believes that her behaviors are triggered in the evenings when male staff members are present, with the intent of having him restraint (sic) her." February 27, 2013

"...she revealed that someone in the hospital raped her." May 1, 2013

"She reported that the same person that raped her in the past was working at the hospital during her last visit, and raped her again." December 3, 2013

Hampton-Newport News Community Services Board progress notes

H-NN CSB has been the one consistent provider in Brittany's life since she was a child. They know her better than any other service provider in Virginia. H-NN CSB has failed in numerous ways to coordinate Brittany's care, to support Brittany in the community, and to advocate for appropriate care. H-NN CSB is aware of Brittany's trauma history and the abuses that have occurred in institutional care. H-NN CSB has actively supported placing Brittany in institutional settings when they failed to identify or create needed community supports. H-NN CSB has on multiple occasions failed to obtain or provide professionally recommended services. Professionals have repeatedly stated that Brittany's crises are often behavioral, not psychiatric, in nature and identified the need for behavioral supports. However, records indicate that Brittany had a behavioral support specialist in the community for only 7 of the 30 months between April 2013 and October 2015. Without supports in place, Brittany continued to interface with the crisis service system, and both mental health facilities and jails.

[ESH Psychiatrist] stated...her behavior does not warrant her continued hospitalization, as 'this is not the least restrictive environment for her'." November 14, 2014

"...Director at MCV was recommending discharge due to ongoing behavioral concern, not related to acute [mental health] needs." July 11, 2014

"...[Brittany] remaining at the hospital is not of service to her." March 9, 2013

"[Brittany's] behavioral outburst this weekend was not a mental health crisis but a behavioral crisis." October 9, 2012

Hampton-Newport News Community Services Board progress notes

In the spring of 2015, Brittany was involuntarily committed¹¹ to Virginia Commonwealth University's (VCU) psychiatric unit. VCU was prepared to discharge Brittany to a homeless shelter¹² because H-NN CSB had once again not secured a housing provider. H-NN CSB instead advocated for transfer to ESH even though VCU's experts planned to discharge her to the community because she did not require further inpatient care. ESH's psychiatrists have repeatedly indicated that ESH is counter-therapeutic and "an over-stimulating environment for Brittany."¹³ Within days of re-admission to ESH, she was placed in the emergency restraint chair¹⁴ (ERC) and was placed in the ERC 17 more times during the following five and a half months.¹⁵ Two months into her stay, peers assaulted Brittany on two occasions.¹⁶

During this admission to ESH, staff pressed assault charges on Brittany for the same behaviors that led to her hospitalization. As a result, in December 2015, ESH discharged Brittany to Peninsula Regional Jail. Upon discharge from jail, she had no place to go. In theory, the crisis program (REACH¹⁷) should have been an option for her. "This statewide system is designed to meet the crisis support needs of adults who have an intellectual and/or developmental disability and are experiencing crisis events who put them *at risk for homelessness, incarceration, hospitalization, and/or danger to self or others.*"¹⁸ However, the REACH program stated they could not support Brittany after her jail discharge due to staffing issues.¹⁹ In addition, REACH staff recommended that Brittany "complete her 180 day admission to a state hospital"²⁰ even though her treating psychiatrist had already determined she did not need inpatient care. H-NN CSB identified a group home for Brittany on the morning of her release from jail and dropped her off later that day without all of her psychiatric medications.²¹ Once again, Brittany was not appropriately supported in the community and was set up for failure, subsequently being admitted to a community hospital for self-injurious behavior.

By January 2016, Brittany was again inpatient at ESH even though ESH had proved to be unsafe. The ESH psychiatrist applauded her ability to use her coping skills in the midst of a stressful and chaotic unit²² emphasizing that he understood how the environment challenged her. By mid-February, ESH's psychiatrist stated that Brittany did not need inpatient care. Even though her treatment team at ESH agreed she no longer needed to be served in this acute facility, she was re-committed for another 30 days on February 24, 2016 because she had nowhere else to go. H-NN CSB had once again failed to secure the needed community supports for Brittany.

H-NN CSB has concluded there are no group home providers willing to accept Brittany. This strains belief because the Commonwealth has 518 licensed residential providers²³ that accept the type of funding Brittany has available. H-NN CSB sought support of DBHDS's leadership to find Brittany needed services in December 2015.²⁴ In January 2016, DBHDS developed an interim plan until a community provider could be identified or developed. The Commonwealth presented Brittany with one option - transfer to another state-operated institution - Southeastern Virginia Training Center (SEVTC). SEVTC is an intermediate care facility (ICF) for individuals with I/DD (commonly known as a training center). This option, while not the least restrictive, is all the state has to offer. Shockingly, this is in the midst of the

ongoing settlement agreement to address the state's continued reliance on institutional care for individuals with I/DD instead of integrated community services.

Brittany liked the plan and was hopeful about starting over at SEVTC. Many meetings were held and detailed information about her support needs was shared. After taking two visits to SEVTC, Brittany was admitted on March 24, 2016. On March 26, 2016, she was discharged from SEVTC and recommitted to ESH after she displayed a known and expected behavior. Brittany reports that, during the behavior, she requested but was denied anxiety medication which she had been receiving at ESH. REACH was not present during the crisis. The system once again failed to meet her needs and has re-traumatized her. As of the end of March, she remains on the same stressful and chaotic unit at ESH that psychiatrists have determined is "an over-stimulating environment."²⁵ The ESH psychiatrist has again stated Brittany does not require inpatient psychiatric treatment; however, SEVTC has now requested more testing and information before re-admitting her, in addition to proclaiming they do not provide mental health treatment. The Commonwealth's fragmented system is rejecting Brittany and individuals who are dually diagnosed. There is no safety net.

The state's plan is to transition her into the community once a residential provider that can provide appropriate services and supports is identified or developed. The success of the plan is primarily in the hands of H-NN CSB and ultimately DBHDS through the performance contract. She is relying on H-NN CSB and is somewhat apprehensive based on their previous inadequate case management services. Additionally, DBHDS has to improve overall behavioral health and crisis services to stop re-traumatizing Brittany and other individuals who are dually diagnosed by offering only unnecessary and inappropriate admissions to psychiatric facilities. If a provider is not developed or found, Brittany may remain in an institution indefinitely, through no fault of hers but the system's failures.

Conclusion:

Gaps in Virginia's system of care cause great harms and continue to foster institutional care. There is no adequate or intact safety net for all dually diagnosed individuals. To the Commonwealth's credit, they are successfully implementing post-move monitoring for individuals with I/DD who are leaving state-operated intermediate care facilities (ICFs). Some of these individuals are dually diagnosed. Post-move monitoring is designed to "identify gaps in care and address proactively any such gaps to reduce the risk of *re-admission, crises, or other negative outcomes*."²⁶ An expert "has continued to find that the Commonwealth has successfully implemented and refined a discharge planning and post-move monitoring processes."²⁷ Unfortunately, not all individuals within the settlement agreement's target population are provided with this exemplary service and therefore are more easily subjected to unnecessary institutionalization. The state has now agreed to provide post-move monitoring for Brittany. However, these issues are not unique to Brittany. dLCV is aware of many individuals who are dually diagnosed and who are unnecessarily institutionalized or jailed after failed crisis services.

The Commonwealth can help Brittany and others similarly situated if they choose to; however, they must be proactive. Individuals who are dually diagnosed are particularly vulnerable in the splintered system. Virginia must improve the crisis service system so people have access to quality crisis services that prevent institutionalization. Providers who have abused or neglected people need to be held accountable. The Commonwealth should provide post-move monitoring for all people identified in the settlement agreement's target population who are leaving institutional care, not just state-operated ICFs. dLCV is hopeful that post-move monitoring will be one piece of a safety net for Brittany as she enters the community where she hopes to finish school and start working; however, more must be done to mend the system for all.

We hope that the next placement option offered to Brittany will be one that respects her desire for real supports that allows her to pursue the dreams that have been long ignored. We urge the Commonwealth to adopt practices that do not punish its service recipients for the conditions and behaviors that are already recognized and diagnosed. The Commonwealth must stop making its clients pay for the Commonwealth's own systemic failures. Brittany deserves to finally have a safe, stable home with appropriate services and supports.

¹ Diagnosis upon admission to Eastern State Hospital, January 2016

² Email dated December 29, 2015 from Hampton-Newport News Community Services Board

³ Americans with Disabilities Act (ADA)

⁴ United States v. Commonwealth of Virginia Settlement Agreement, August 2012

⁵ Report of the Independent Reviewer on Compliance with the Settlement Agreement, United States v. Commonwealth of Virginia, October 7, 2014 – April 6, 2015, page 43

⁶ Diagnosed with an intellectual or developmental disability and mental illness

⁷ Psychiatric Evaluation, February 11, 2002, Hampton Newport News Community Service Board

⁸ Psychiatric Evaluation, February 11, 2002, Hampton Newport News Community Service Board

⁹ Email dated December 29, 2015 from Hampton Newport News Community Services Board

¹⁰ Hampton-Newport News Community Services Board progress notes, October 20, 2014

¹¹ Court ordered to receive psychiatric treatment

¹² Hampton-Newport News Community Services Board progress notes, May 13, 2015

¹³ Eastern State Hospital Discharge Summaries, August 27, 2014 and January 14, 2015

¹⁴ Hampton-Newport News Community Services Board progress notes, June 1, 2015

¹⁵ Eastern State Hospital seclusion and restraint documentation, May 30, 2015; June 10, 2015; June 12, 2015; June 20, 2015; June 24, 2015; July 4, 2015; July 13, 2015; July 14, 2015; July 19, 2015; August 2, 2015 (2 episodes); August 3, 2015; August 12, 2015; August 14, 2015; August 19, 2015; August 30, 2015; October 17, 2015, and October 18, 2015

¹⁶ Eastern State Hospital Brief Treatment Plan Summary, 7/9/15 and 7/23/15

¹⁷ Regional Education Assessment Crisis Services Habilitation

¹⁸ REACH Program Standards (emphasis added), August 31, 2015, page 3

¹⁹ Hampton-Newport News Community Services Board progress notes, December 30, 2015

²⁰ Hampton-Newport News Community Services Board progress notes, December 30, 2015

²¹ Hampton-Newport News Community Services Board progress notes, January 1, 2016

²² An admissions unit for individuals who have acute psychiatric symptoms.

²³ Department of Behavioral Health and Developmental Services licensed residential providers and sponsored residential providers that accept the Intellectual Disability (ID) Waiver, provided by Dr. Cleopatra Booker on February 2, 2016

²⁴ Email from Hampton-Newport News Community Services Board to Department of Behavioral Health and Developmental Services Central Office, dated December 29, 2015

²⁵ Eastern State Hospital Discharge Summaries, August 27, 2014 and January 14, 2015

²⁶ United States v. Commonwealth of Virginia Settlement Agreement (emphasis added), August 2012

²⁷ Report of the Independent Reviewer on Compliance with the Settlement Agreement United States v. Commonwealth of Virginia, April 7, 2015 – October 6, 2015, page 65

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