

Commonwealth of Virginia

*Virginia Board for People with Disabilities*

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August 19, 2014

TO: Dr. Dawn Adams, DD Health Care Specialist, *DNP, ANP-BC, CHC*

Dept. for Behavioral Health and Developmental Services FROM: Heidi L. Lawyer 

CC: Connie Cochran, Assistant Commissioner, DBHDS

RE: *Developmental Disabilities Health Support Network Overarching Plan Draft*

I am writing on behalf of the Virginia Board for People with Disabilities (the Board) to provide written comment on the aforementioned *Developmental Disabilities Health Support Network Overarching Plan Draft*. The Board appreciates the Department’s work to support meaningful system changes which improve the scope, quality and effectiveness of community services/supports for all individuals with an intellectual or developmental disability (ID/DD). The Board did not have the opportunity to provide comment on the February 2014 *Developmental Disability Health Supports Network Proposal.* However, in March 2014, the Board did provide comment on the draft *Implementation Plan for Serving Youth and Adults with High Medical Needs* and expressed significant concern regarding its lack of comprehensive breadth and depth regarding action steps/activities and accountability.

This new plan, as an overarching draft, addresses a number (although not all) of the issues identified in the Board’s March 2014 comments as it incorporates the delivery of services to the

ID/DD population as a whole, with a focus on those transitioning from institutions. This high level draft, which will ultimately need more details, timelines, and specific objectives, is thoughtful and comprehensive. It is a significant improvement over earlier drafts relating to healthcare delivery, which did not put forward significant structural changes to the system that would result in real transformation to a person centered health care system.

Key issues are identified, including those related to serving children and the continuing need to address dental services for the population of individuals with ID/DD. The Virginia Board for People with Disabilities has had a longstanding focus on expanding the availability of dental care for adults with ID/DD. In addition to consistent recommendations for covering dental services under the Medicaid state plan or as a Medicaid waiver service, the Board has funded two grants (one in progress with the Virginia Oral Health Coalition) to improve statewide capacity.

The “Integrated Dental Service Initiative” program (2010-2011), conducted by NVTC, increased capacity in Northern Virginia for dentists who can and are willing to treat patients with developmental disabilities by providing training and interactive dental workshops for 244 dental professionals. In addition, the grant program provided free dental care for 103 patients during and after the workshops. (As a result of this program, there is a database of dentists in Northern Virginia who are willing to treat patients with special needs and The Arc of Northern Virginia now has a list of dentists to whom patients with ID/DD can be referred. The program also resulted in an externship program at VCU Health Systems. In 2013, this program was replicated through the “Oral Health for Adults with DD” program (2013-2015) conducted by the VA Oral Health Coalition, serving Richmond, Lynchburg, Chesapeake and Fairfax. As of June 2014, two training sessions/dental clinics have been conducted (in Richmond and Lynchburg), training 42 dental professionals and providing free dental care to 20 individuals with developmental and other disabilities. The outcomes from these grants may be helpful for the department to consider as it moves forward.

The Board supports the draft plan’s emphasis on telemedicine as an important support for consultation to providers who may be new to serving this population. We also support the need for core university curriculum changes and significant collaboration with key agencies, statewide medical and provider organizations, and healthcare systems, among others. Other areas of significant need include an increased focus on prevention and wellness, (including but not limited the development of (and billing for) services that could, for example, an individual to attend a gym or health club to maintain wellness and avoid future healthcare costs.) Medication issues, particularly over medication and/or inappropriate use of psychotropic medication (particularly for behavioral issues) will need ongoing, continued vigilance and clear assessment protocols as individuals are integrated into new settings and communities.

The Board strongly supports the emphasis in this plan of integrating individuals with ID/DD, including those with the most significant needs, into the current health care system vs. creating a parallel system of services. We recognize that this will take time and intermediate steps are necessary to ensure quality health care to individuals transitioning from institutional settings into the community, as well as to those individuals already living in the community who need improved

access to quality health care. Building provider willingness and capacity through education and training is an essential component of systems transformation.

The Board appreciated the response to this draft plan as delivered by Susan Rudolph from the Arc of Prince William at the August 13, 2014 DOJ Stakeholders’ meeting. Ms. Rudolph and the Arc have successfully transitioned to a community-based model of health care services and their experiences and challenges should be shared throughout the Commonwealth, as should the experiences and challenges of other providers who have transitioned to individualized, person centered models of care and those who are having difficulty doing so. The focus in the plan on extensive data collection and analysis, including gap analysis, will be of great benefit to improving local, regional and statewide efforts and systems.

While the Board does not currently have a position on having Developmental Disability Health Care Centers (operating as the Regional Community Support Centers) have done, the point made by Ms. Rudolph regarding the establishment of “temporary” infrastructures ending up being permanent infrastructures is worth additional discussion and consideration. The Board agrees that once buildings and centers have been established, it may be more difficult to transition out of a center based approach. We also recognize that it will take time build a fully integrated person centered health care system and are open to how this can best be accomplished.

Assessment of health outcomes is another critical component of the plan, particularly as individuals with ID/DD move from institutional to community-based settings. Families of individuals in training centers are concerned about the loss of center based health care services and reporting outcomes in a transparent manner will be important to building trust in the new system. We recognize and support the increased use of nursing staff and, where appropriate and needed, nurse case managers, particularly for those individuals with high medical needs. It will be important to analyze the scope of services that nurse case managers will undertake to avoid duplication (including in cost) to CSB or private case managers that may be working with the same individual(s).

The Board believes that this overarching plan moves the Commonwealth forward in its long- awaited transformation effort. As the plan moves forward and becomes more detailed, the Board recommends that it include:

* measureable short, mid- and long-term goals that reflect the desired outcomes for individuals with ID/DD;
* specific desired outcomes for those with ID or DD who have high medical needs;
* milestones to achieve for each goal, the person responsible, and resources needed; and
* a formal evaluation process, including the methods by which valid and reliable data will be collected to effectively track progress in reaching the milestones.

The Board appreciates the opportunity to be a participant in the DOJ Settlement Agreement planning and to provide comments to the Implementation Plan. Please contact me at 804-786-9369 or Heidi.Lawyer@Vbpd.Virginia.gov if you have any questions or need additional information on our comments.