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TO: Dawn M. Adams, DD Health Care Specialist, PhD, DNP, ANP-BC, CHC
Department for Behavioral Health and Developmental Services (DBHDS)

FROM: Heidi L. Lawyer Heidi Lawyer

CC: Connie Cochran, Assistant Commissioner, DBHDS

RE: *Nursing Facility and Large ICF/IID Overarching Plan Draft (August 2014)*

I am writing on behalf of the Virginia Board for People with Disabilities (the Board) to provide written comment on the aforementioned *Nursing Facility and Large ICF/IID Overarching Plan Draft (August 2014).* The Board recognizes and appreciates the thoughtful effort involved in developing this draft plan, which is more detailed. The Board strongly supports the Commonwealth's goal of reducing placement of youth and adults with ID/DD in institutions per the Settlement Agreement with the U.S. Department of Justice.

First and foremost, the Board urges that the plan be revised to increase emphasis on informed choice of the individual adult or youth (ages 18 -22 years old). Language on page 9 under Implementation/Discharge Process for Nursing facilities repeatedly references the criteria (using various language), "… *individual, parent, guardian/AR is agreeable to discharge.*" The Board recommends that DBHDS, in collaboration with the Virginia Department of Health Office of Licensure and Certification and with the Department of Medical Assistance Services, ensure full compliance with the federally required Return to Community Assessment (also known as MDS Section Q) for youth in nursing facilities.

Relatedly, an adult or youth (ages 18 or older) who is placed in a nursing facility or large ICF/IID may have different preferences for their residence than their parent or guardian. Of concern to the Board is that Virginia's legal system typically grants full guardianship of individuals rather than consider limited guardianship based on a formal assessment of the individual's capacities and abilities. The language of the DBHDS plan, in this section in particular, appears to weigh parent/AR/guardian preferences over that of the youth.

Additional comments will be made by section and page number of the plan. For purposes of Board comments, "large" institutions are defined as 16 beds or more. This definition is used for national reports on ID/DD residential patterns prepared by the University of Minnesota Center for Community Integration and by the Coleman Institute at the University of Colorado.

Background (pp. 2-3)

The Board concurs with the draft plan that careful, well-planned transitions to the community are critical to the health, safety and welfare of all individuals–youth and adults–currently residing in institutions. Although a reminder on the importance of thoughtful planning for transitions is appropriate, the text on deinstitutionalization fails to credit the "lessons learned," as evident in the later downsizing of psychiatric facilities by DBHDS in the 1990s. The Board recommends that text be added to address the following:

- individuals with ID/DD who live in institutional settings, especially large ones, typically <u>do not</u> have …"co-residence selection, negotiation of staff needs with service users' needs, organizing a culture of engagement in the home and in the community, and focus on quality of life" (p. 2);

- Virginia, like other states, has learned from the mistakes of rapid deinstitutionalization of state psychiatric hospitals during the 1970's. Planning and actions taken as a result of the DOJ Settlement Agreement during the 1990's attest to the deliberate, thoughtful commitment to health, safety, welfare and community integration.

Introduction (pp. 3-5)

This draft plan unfortunately still fails to address the Independent Reviewer's recommendations (Report #2, 2013). The plan does not identify mid- and long-term goals in terms of measurable outcomes for individuals with ID/DD now living in nursing homes and large ICFs/IID. Although a summary of goals and objectives is provided later in the plan (pp. 11-14), it does not identify implementation milestones and timelines for each goal, the resources needed, and the monitoring/evaluation process(es).

The "two strategies" in actuality are goals: 1) *Closing, but not locking, the front door to institutional care for youth*; and 2) *Exiting out the back.* Since 2006, the Board has recommended that the Commonwealth make the necessary legal and regulatory changes to end youth admissions (ages 0 through 21 years) into large nursing facilities or ICFs/IID for long-term care. The Board recognizes that certain medical conditions, especially post-hospitalization, may require follow-up rehabilitative services from a nursing facility. Children with developmental and other disabilities deserve to grow up with their families, and families deserve support to care for them appropriately. Residence in a large institution on a long-term basis, which now occurs, means separation from family and community relationships, and, too often, a weakening of family bonds over time. As noted in the Board's previous comments on the draft plan for the DD Health Network, the Board strongly supports expansion of qualified healthcare and related providers to meet the health and dental needs of youth and adults with disabilities living in their communities.

The strategies to address "Closing the front door" remain overly broad and general. How will the PASRR process be changed? How will the process change lead to planning or development of community resources? The Board recommends that DBHDS also initiate dialogue with key administrators at each of the state medical schools to ensure an adequate future workforce trained to serve individuals with ID/DD. To avoid opening new large ICFs/IID will require more than education and encouragement of providers; overlooked is the ability of current large ICFs to expand readily if each expansion is under 12 beds. The Board recommends that DBHDS, in collaboration with VDH and DMAS, make two key changes in state regulations and licensure: 1) formalize a cap of 6 beds on ICF size for new facilities; and 2) restrict or eliminate expansion of large ICFs currently in operation. In doing so, consideration should be made of financial incentives through differential reimbursement rates based on facility size.

Exit Strategies–Assessment (pp. 5-8)

The Board strongly supports and applauds efforts to enhance data driven decisions. The Board recommends inclusion of the following data for "real time" analysis:

- *Individual*–Include Level of Functioning and ADLs; and whether the child is in foster care. The meaning of "*institutionalization*/medical diagnosis" as well as "dates of last service" is unclear. The factors contributing to the placement must be identified and examined, which may relate to a medical condition but actually pertain more to known available supports.
- *Facility*–In addition to name and location, include bed capacity.

Of grave concern to the Board is the description of ICFs/IID (p.5) as "community-based homes (institutions)." The CMS Final Rule on HCBS Settings is very clear that ICFs are institutions and are not considered a community setting. ICFs are based in localities and are not “homes.” The Board recommends that this description be revised to reflect both federal and state policy.

The bullet on Personal Assistance Services (PAS) provided through the Department for Aging and Rehabilitative Services (DARS) is overly general and thus, misleading. As written, the text indicates that PAS through DARS is available to individuals with physical and/or sensory disabilities. In actuality, PAS requirements are more stringent. Key DARS criteria for the State-Funded PAS include limits on financial resources and that an individual does not qualify for PAS under public insurance (Medicare or Medicaid), private insurance or any other public program. The Brain Injury PAS requires documentation of an assessment of the brain injury by a qualified professional, and a representative who will manage the services. The Board recommends clarification of the criteria.

The description of data on youth in Virginia’s nursing facilities and ICFs/IID (pp. 6-7) raises other issues. The plan notes that a “significant number” of youth did not have recent billing (90 days) under Medicaid; and “it appears that these children have exited the institutional setting.” Of concern is that, although confirmation of the data will occur, there is no stated intent or plan to track what happened to the child. Did he or she die? Move out of state? The Board recommends that the plan specifically include development of a process, in collaboration with VDH and DMAS, so tracking of all youth in institutions can occur. To enhance planning, the Board recommends development of age cohorts as part of ongoing data analysis. (For example: 0 through 5 years old; 6 through 11; 12 through 17; and 18 up to 22.) The type of community supports will vary, to various degrees, based on the individual’s age.

At the end of the second paragraph on page 7, the following statement is made about nursing facilities and ICFs/IID:

> “Though they may be compelled in some cases to allow facility access for purposes of conducting individual assessments, *they are not obligated to ensure patient residency* [*italics added for emphasis*] while investigating community-based resources in an effort to discharge the resident to the community.”

The Board questions the validity of that statement, which implies that these institutions can discharge individuals at will without appropriate discharge plans. For institutions receiving Medicaid or Medicare funds, federal regulations expect the following:

a) conduct required referrals/follow up when an individual indicates interest in information on community options as a result of the Return to Community Assessment (also known as MDS Section Q); and

b) ensure that appropriate discharge planning occurs, i.e. that needed supports and services, including residence, are arranged.

Code of Virginia § 32.1-138.1 also sets forth specific, limited conditions under which discretionary discharges by nursing facilities can occur.

Various accreditation bodies (e.g. CARF, JCAHO) and professional certification bodies have similar clear expectations of appropriate discharge practices. If either a nursing facility or ICF/IID discharges an individual during an exploration of community options before supports are in place, then a complaint should be made to the VDH Office of Licensure and Certification (OLC) as well as to DMAS Office of Quality Management Review (QMR) as well as any other accreditation bodies. The Board recommends that DBHDS collaborate with VDH OLC and the DMAS Office of QMR to have an agreed upon process for monitoring the institution's discharge of youth or adults.

Exit Strategies–Planning (p. 8)

The Board applauds the recommendation to formalize the PASRR process, including oversight to ensure that screenings are complete and current in compliance with federal regulations. The Board is aware that a significant, historical pattern exists in recommendations resulting from the Universal Assessment Instrument process. As noted in the plan, acute hospital staff typically recommend nursing home or institutional placement in 88% of the cases. Given the persistence of these outcomes, which suggest entrenched perspectives, we question the value of further education/training on administration of the Level 1 PASSR. The Board recommends that DBHDS, in collaboration with DMAS and VDH, develop a network of independent evaluators to conduct the PASSR I.

Exit Strategies–Implementation/Discharge Process (pp. 9-10)

The plan notes that a literature review was conducted to identify "best practices" for prioritizing transition/discharge, but no data was found. Another source for information is the ID/DD agency in other states which have significantly reduced use of large ICFs/IID and nursing facilities for individuals with ID/DD. Data on nursing facility and ICF/IID utilization in the national report, *State of the States-9th Edition (2013)*, indicate that:

- **Kansas** no longer has either large, private (16+ beds) ICFs/IID or has any individuals with ID or DD in a nursing facility;
- **Alaska** & **Oregon** no longer have large private ICFs/IID <u>and</u> have very low utilization rates for Nursing Facilities by individuals with ID or DD;
- Other states that no longer have large private ICFs/IID include: Alabama, Colorado, Hawaii, Idaho, Maryland, Massachusetts, New Mexico, South Carolina, Vermont, and Wyoming
- Other states with low utilization rates for Nursing Facilities by individuals with ID or DD were Arizona, California, Nevada, & Washington.

The Board recommends that DBHDS contact these states to gain insight into both strategies which worked well and those that did not.

An existing tool for prioritization of transition/discharge for Virginians (youth and adults) who are in nursing facilities is the Return to Community Assessment (MDS Section Q). The Board recommends that results from this assessment be used for prioritization along with other criteria. As noted earlier, the Board recommends revising the criteria to reflect greater emphasis on individual preferences and informed choice.

Exit Strategies–Implementation/Diversion (p. 10)

The Board concurs that revising the current PASSR process and creating an effective DD Health Support Network is important for successful diversion into nursing facilities. As we noted in our comments on the draft DDHSN overarching plan, the DDHSN should not become a parallel healthcare system. Instead, DDHSN planning should include meaningful engagement of critical partners such as the state medical schools and various statewide associations of medical/health professionals. In recent years, national dental and medical school curricula certification standards have included the expectation of training to enable better services to special populations, including individuals with disabilities and the elderly, among others. The medical schools prepare the next generation of providers. Both the schools and professional associations provide coursework for Continuing Medical Education credits to current licensed practitioners that expand expertise. The Board recommends that implementation include outreach to and engagement of these organizations.

Specific Organizational Challenges (pp. 10-11)

The Board urges caution about potential duplication of existing efforts regarding two of the identified challenges: "…develop a resource list identifying community supports," and "create and establish educational programs for residential, family and day providers." For the former, the Commonwealth has in place both VirginiaAccess and VaNavigator for resource information. In addition, each Community Service Board should have its own process for maintaining regional resource information for use by its case managers. Regarding the latter challenge, the purpose and topics of the educational programs is unclear. What is the "education" gap being addressed? What efforts are or have been underway to provide the education? The Board recommends that DBHDS build on existing initiatives whenever possible to achieve its goals rather than create new, potentially duplicative, services.

The Board appreciates the opportunity to provide comments on this draft plan. If you have any questions or need additional information, please contact me at Heidi.Lawyer@vbpd.virginia.gov or by phone at 804-786-9369.