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March 27, 2014

TO: Dawn Traver, M.Ed., Community Resource Manager, Office of Developmental Services
Beverly Morgan, MSG, PASRR Consultant and Gerontologist (DBHDS)

FROM: Heidi L. Lawyer Heidi Lawyer

CC: John Pezzoli, Acting Commissioner, DBHDS
Connie Cochran, Assistant Commissioner, DBHDS

RE: Draft *Implementation Plan for Increasing Community Options that Support Youth and Adults with Intellectual and Developmental Disabilities with High Medical Needs in Integrated Settings*

I am writing on behalf of the Virginia Board for People with Disabilities (the Board) to provide written comment on the aforementioned Draft Implementation Plan. The Board has been engaged in a stakeholder group regarding this initiative and continues 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 has been, and remains, concerned that there has been insufficient planning and attention to address the needs of youth and adults with ID/DD who have high medical needs. We support a number of the changes identified in the plan but have overall concerns.

The most recent Report of the Independent Reviewer on Compliance (December 6, 2013) states the following:

> *"The DBHDS added new members to the workgroup from DMAS and drafted the work plan entitled: **"Children in Nursing Homes and ICFs."** This work plan outlines a process by which representatives of DBHDS, DMAS, independent experts and stakeholders "will develop a **long term plan** to reduce the number of*

> *children with ID/DD living in nursing homes, the largest ICFs/IDD and long-stay hospitals, and to reduce the risk of new admissions to these facilities for individuals with ID/DD of all ages." The goals of the plan involve assisting children and adults to move out of these facilities and implementing strategies to redirect potential admissions to community-based alternatives."* [page 17]

It is the Board's understanding from the IR report is that the foundation for the development of the Implementation Plan is the work plan referenced above:***"Children in Nursing Homes and ICFs***." That work plan has not been made public which limits our ability (and the ability of others) to align the implementation activities with that work plan. As a result, our comments are limited to what is provided in the Draft Implementation Plan. In making our comments, the Board therefore assumes that the Draft Implementation Plan is intended to serve as the "**long term plan…"** referenced above.

The first paragraph of the draft Implementation Plan includes the following Independent Reviewer's Recommendation (Report # 3 – April 7, 2013 –October 6, 2013): *"Complete an implementation plan by March 31, 2014 that includes measurable mid- and long-term goals that reflect the desired outcomes for individuals with ID/DD (living in nursing homes and large ICF/IDDs). The plan should identify implementation milestones to achieve for each goal, the person responsible, the resources needed, and an ongoing evaluation process. The plan should identify how long term success will be measured, and the means and methods by which data will be gathered to evaluate its progress."*

It is the Board's opinion that the draft Implementation Plan is deficient in meeting the following criteria included in the independent reviewer's recommendation:

- Measureable mid-and long-term goals that reflect the desired outcomes for individuals with ID/DD (living in nursing homes and large ICF/IDDs)
- Implementation milestones to achieve for each goal, the person responsible, resources needed, and, an ongoing evaluation process
- How long term success will be measured, and the means and methods by which data will be gathered to evaluate its progress.

The Draft Implementation Plan overall lacks the comprehensive breadth and depth regarding action steps/activities and accountability standards one would expect of such a plan. It fails to provide a clear overview of the operational changes that must be made at DBHDS and system-wide to improve progress on this Settlement Agreement.

As written, the Draft Implementation Plan does not appear to incorporate collaboration with key agency partners such as the Department of Medical Assistance

Services (DMAS), the Department of Health, key statewide medical organizations, and professional associations for pediatric physicians and nurses, among others.

The information provided under the section, *Outline of Changes to Virginia's System (pp. 3-8)*, is overly broad and not adequately explained. It does not provide any detail on how the process/operational improvements nor how they are likely to impact "*the desired outcomes for individuals with ID/DD.* " The list of changes infers that Medicaid Waiver changes rather than data-driven decisions on the types and scope of new or expanded community services needed are the first step.

The Board does support a number of the changes identified including those related to changes to PASSR Level II Screening. The Board supports the identified improvements in processes, staffing and operations, enhancements to PASRR Level 1 and II Assessments, time-limited respite residential care for up to 90 days, and the hiring of nursing personnel within DBHDS.

However, as a whole the Board believes that as currently crafted, the draft plan is inadequate in (1) meeting key Settlement Agreement items related to nursing home/ICF-ID transitions and prevention of institutional placement components and (2) the Independent Reviewer's recommendation and general expectations. Lack of data analysis on the current population to be addressed per the Settlement Agreement is a significant shortcoming and omission in the Outline for Changes and Timeline. None of the planned activities under the Timeline can be effectively achieved without in-depth knowledge of population's demographics, medical and functional needs, which are likely to include identifiable sub-groups which have unique support needs. Conducting such an analysis should be identified within the plan. The Board recommends that the following be considered as part of Plan revision.

- ➢ Develop measureable mid-and long-term goals that reflect the desired outcomes for individuals with ID/DD.
- ➢ Identify specific desired outcomes for those with ID or DD who have High Medical Needs.
- ➢ Identify and develop milestones to achieve for each goal, the person responsible, and resources needed.
- ➢ Develop and implement a formal evaluation process, including the methods by which valid, reliable data will be collected, to effectively track progress in reaching the milestones.
- ➢ Incorporate and describe participation by new DBHDS nursing personnel and other key stakeholders from DMAS, the VDH Office of Licensure and Certification (as indicated), key medical association representatives, advocates, individuals with disabilities, and families.

In March 2014 the Association of Maternal & Child Health Programs (AMCHP) released *Standards for Services of Care for Children and Youth with Special Health Care Needs*, a product of the National Consensus Framework for Improving Quality Systems of Care for Children and Youth with Special Health Care Needs. The publication includes a core set of structure and process standards for systems of care for children and youth with special health care needs. Dr. Colleen Kraft, an innovator of the Medical Home model in Virginia, was a member of the workgroup. DBHDS may find some of the standards and benchmarks a useful resource: http://www.amchp.org/AboutAMCHP/Newsletters/member-briefs/Documents/Standards%20Charts%20FINAL.pdf.

The publication describes children and youth with special health care needs (CYSHCN) as "a diverse group of children ranging from children with chronic conditions such as asthma or diabetes, to children with autism, to those with more medically complex health issues such as spina bifida or other congenital disorders, to children with behavioral or emotional conditions." While primarily targeted to state Title V CYSHCN programs, the recommendations are application to other state agencies and groups (e.g., Medicaid, Early Intervention, Developmental Disabilities, Children's Health Insurance Program). The publication's intention is to assist states with developing a comprehensive, quality system of care for children and youth with special health care needs, including those transitioning from institutional settings.

The following core domains for system standards are identified:

1) Screening, Assessment and Referral
2) Eligibility and Enrollment
3) Access to Care
4) Medical Home, including:
    - Pediatric Preventive and Primary Care
    - Care Coordination
    - Pediatric Specialty Care
5) Community-based Services and Supports, including:
    - Respite Care
    - Palliative and Hospice Care
    - Home-based Services
6) Family Professional Partnerships
7) Transition to Adulthood
8) Health Information Technology
9) Quality Assurance and Improvement
10) Insurance and Financing

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 if you have any questions or need additional information on our comments.