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November 19, 2009

James Reinhard, M.D., Commissioner
Department of Behavioral Health and Developmental Services
1220 Bank Street
PO Box 1797
Richmond, VA 23219-1797

RE: DBHDS Comprehensive State Plan, 2010-2016 (Nov. 16, 2009)

Dear Dr. Reinhard:

I am writing to provide public comment on behalf of the Virginia Board for People with Disabilities (hereafter referred to as VBPD) regarding your draft Comprehensive State Plan for 2010-2016. We deeply appreciate the affirmation of priorities, vision and values identified in its Integrated Strategic Plan (pages 20+). The Department's continued commitment to person-centered and family-centered principles is commendable as is the strong focus on building community supports and infrastructure.

The Board's comments below are organized by Page number and are related to the areas in which the Board works, or has specific, knowledge or expertise. As such the comments focus on plans, services and supports for individuals with developmental disabilities and do not address programs and services relevant to individuals with mental illness or substance abuse challenges/

Page 16, 1st sentence – Estimated Prevalence for Individuals with Disabilities - We recommend that the adjective "conservatively" be added before "estimate". The ADD/ACF prevalence rate has been used for a number of years and, in light of more recent data on autism spectrum disorders, is probably an under-estimate.

Page 18, Last table, Length of Time on CSB Waiting Lists for All Services, Jan.-April 2009: Some explanation of the data presented would significantly enrich an understanding of the service system. Inclusion of information about the specific CSB services for which individuals are waiting could provide a picture of community needs, especially for those waiting 4 years or more (49+ months).

Relatedly, to what extent are waits for CSB services related to waiting for a Medicaid Waiver? In other words, are some CSB services funded exclusively through Medicaid, and individuals who are on Waiver wait lists therefore cannot access them and are also on the CSB service wait list

Pages 22, bullet on continuous quality improvement, and Page 30, 2nd paragraph – Community Integration. VBPD thanks the Department for including community integration as a core outcome measure for the system. Community integration is a core goal of the 2000 Developmental Disability and Bill of Rights Act, PL 106.402 (the "DD Act"). Of concern to us, however, is the definition adopted (p. 30) for community integration, which is narrow in scope and could be used to justify having an individual remain daily at a facility, only seeing individuals from the community as visitors or volunteers. The Office of the Inspector General, in collaboration with stakeholders, developed the following operational definition for his 2007 systemic review of Training Centers:

> "*Community Integration: There are two aspects to community integration which are important. These include having a community presence through ongoing and regular use of the "ordinary places" in the community such as restaurants, parks, shops, and other service locations; and having opportunities for community participation. Community participation involves individuals becoming a part of the mainstream of community life by being a full member. Active involvement in settings designed for work, play, and worship are examples of ways all individuals can interact with the community–at-large*."
> Review of Self-Determination and Person-Centered Experience of Individuals Served in Training Centers Operated by DMHMRSAS (Report # 139-07)

Indeed, the OIG reported finding a lack of "routine opportunities for each person to experience community integration" at the Centers. While later updates indicate some improvements being made at the Centers, the need for continued efforts is clear in his continuation of active findings.

We strongly urge you to adopt a standardized definition for community integration consistent with the definition established by the 2000 DD Act which is:

> "*the term 'integration', used with respect to individuals with developmental disabilities, means exercising the equal right of individuals with developmental disabilities to access and use the same community resources as are used by and available to other individuals*".

Pages 33 – 35, Implementation of Evidence-Based and Best Practices: The VBPD recommends an editorial change and a content addition. Moving the "Evidence-Based Practices for children and adolescence…" list to the top of page 35 would help emphasize the initiatives related to these clinical practices. A heading for best practices in serving individuals with intellectual disabilities or autism spectrum disorders would be helpful. An important statement on best practices for autism that should be considered for inclusion is that early identification and intervention has been found to ameliorate symptoms and improve functioning for many youth.

Page 40, 1st & only paragraph: The number of persons "ready for discharge" is significantly below counts cited in previous DBHDS Comprehensive Plans and OIG facility review reports. For example, the 2010-14 Comprehensive Plan stated that 140 were "ready for discharge". Is 10 (the number cited as of august 2009) the correct number? The text could benefit from clarification of whether these 10 individuals are in the process of discharge. If this count is correct, it would be useful to know the reasons for this dramatic decline or to acknowledge the decline. (As you may recall from previous comments to other documents, VBPD has questioned the "ready for discharge" definition/criteria for individuals in Training Centers. The current definition is based on a medical model that does not apply to individuals with developmental disabilities. That said, VBPD recognizes that the Comprehensive Plan is based on the current definition.)

Page 44, Autism Spectrum Disorder and Developmental Disability Services: Editorially, since the manager positions have been filled, an updating of the verbs and language would indicate progress made. Citing any specific goals during the biennium for each position would be helpful to introduce readers to the initiative. In the fourth paragraph, a housing study is referenced, but little context is provided. Additional information would be helpful to readers.

Page 51, 1st dark bullet, CIT Initiative: As written, promotion of the law enforcement CIT programs is directed only to individuals with mental health or substance abuse disorders in crisis. Based on the last meeting of the Mental Health/Criminal Justice Consortium, VBPD's understanding was that this initiative, in some localities, also addressed the individuals with intellectual disabilities in crisis, and that the initiative was going to expand its focus to include not only individuals with ID but also with autism. If that is so, adding language regarding inclusion of these populations would be appreciated and would demonstrate further commitment to serving these individuals.

Pages 63-65, State Training Centers: The VBPD applauds the Department's stated intent to *provide services at training centers "only until an appropriate community residence is available." as well as its focus on elimination of the waiver waiting lists, and development of state funded housing and community supports infrastructure.* More information on current or future specific goals, initiatives and timelines towards accomplishing this transition is needed and appropriate. Also, while it is mentioned later under Goals, Objectives and Action Steps, the VBPD must note the glaring omission in this section of the 2009 legislative decision to rebuild Southeastern Training Center at 75 beds and – (and the implication of this decision in terms of building community resources). It would also be appropriate to note the dedication, for the first time in Virginia – of capital outlay moneys for community housing and plans related to these moneys and include detail regarding goals, initiatives and timeline.

Page 67, Objective # 1 under Goal 3: To move the system forward towards this goal, the addition of a goal specifically regarding Training Center services and their future role is recommended.

Page 70, Objective # 7: VBPD recommends inclusion of individuals with ID/DD, including autism spectrum disorders as target populations under this initiative (see comments above for page 51).

Page 72, Objective #10: VBPD recommends expansion of this objective to include the DD/ID population by adding, "*or with co-occurring mental health and developmental/intellectual disabilities*".

Page 78, 3rd paragraph: While the list of conditions that limits, reduces or jeopardizes private provider participation is excellent, the VBPD would recommend addition of two other conditions that significantly impact availability of providers:

- Lack of state and federal subsidies or initiatives to expand affordable housing – Some individuals with DD/ID want apartments of their own and do not need or desire congregate environments. However, for those receiving SSI or SSDI, the affordability gap for apartments is significant. This issue is addressed in-depth in the upcoming legislative study, lead by DBHDS: *Report on Investment Models and Best Practices for the Development of Affordable and Accessible Community Based Housing for Persons with Intellectual or Developmental Disabilities (Item 315 Z).*
- Inadequate or lack of funding for non-Waiver services. In addition to the Medicaid Waiver Wait Lists, there are wait lists for important supports such as personal assistance services and community rehabilitation case management (DRS programs).

Page 80, Objective #1 under Goal 9: The VBPD recommends addition of the following action step – "Work with DMAS to establish Medicaid coverage for dental services to adults under all Waivers." Access to dental services is a very important issue for Virginians with ID/DD. As seen in the death of an adolescent in Maryland last year, lack of regular dental care can lead to major health complications which are much more costly to treat.

VBPD again thanks the Department and the State Board for DBHDS for this opportunity to provide input and comments for the Comprehensive State Plan. We hope that our comments are helpful as you consider final revisions. Please call me if you have any questions or would like additional information from the Board's perspective.

Sincerely,

Heidi L. Lawyer

Cc: The Honorable Marilyn Tavenner, Sec. of Health and Human Resources
Charlene Davidson, Director of Planning and Development
Ruth Anne Walker, Legislative Manager
Heidi Dix, Deputy Commissioner
Teja Stokes, Assistant Commissioner
Frank Tetrick Assistant Commissioner
VBPD Board