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Kim Snead, Executive Director
Joint Commission on Health Care
900 East Main Street, Suite 3072-E
P.O. Box 1322
Richmond, VA 23218

Dear Ms. Snead:

Thank you for the opportunity to provide comment on the proposals resulting from the Joint Commission on Health Care, Behavioral Health Subcommittee, Workgroup on Autism. The Virginia Board for People with Disabilities was pleased to participate in this workgroup with so many interested organizations and individuals committed to finding a state agency home for persons with autism. The Board is an important partner in policy and planning for effective and meaningful systems change and is representative of many constituent groups involved in and profoundly affected by systems change decisions.

In submitting these formal comments, the Board is fulfilling state and federal legislative mandates as well as the agency's mission and strategic vision for people with disabilities:

Under the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402, the DD Act), the Board is directed to "support and conduct activities to eliminate barriers to access and use of community services by individuals with developmental disabilities, [and to] enhance systems design and redesign ..." (Sec.125).

Under the Virginians with Disabilities Act (*Code of Virginia*, Title 51.5, the VDA), the Board is directed "to advise the Secretary of Health and Human Resources and Governor on issues and problems of interest to persons with disabilities" (§51.5-33).

The Board's mission statement is "to improve the lives of people with disabilities by providing a voice for their concerns ..."

Its strategic vision includes a strong commitment to community inclusion to ensure that individuals with disabilities "be given equal opportunity to achieve independence, contribute to society, and enjoy full inclusion into the educational, economic, political, social, and, cultural life of the community."

The Board shares the concern of families, professionals, and advocates and our legislature regarding the growing needs of persons with autism, particularly in light of the exponential growth in this population. The Board also, however, sees a strong need to work towards an integrated service system and supports the consensus recommendation of the workgroup and the following two policy options:

Option 3: Introduce Joint Resolution and/or Budget Amendment Requesting that the Secretary of HHR Develop & Report to Chairmen of HAC, SFC, and JCHC on Implementation Plan to redesign and rename DMHMRSAS to become the primary State agency responsible for serving individuals with developmental disabilities (new responsibility in addition to DMHMRSAS' current responsibilities); or

Option 9: Introduce legislation and accompanying budget language to redesign DMHMRSAS to serve individuals with developmental disabilities.

The Board understands the autism community's frustrations and desire to move quickly, particularly the position of Parents of Autistic Children (POAC) which provided the "minority report" in the presentation to the Joint Commission, Behavioral Subcommittee on September 19. Their concerns are valid and need to be addressed. However, the Board believes that the best interests of our citizens with disabilities are served by a system that does not fragment populations by disability categories. In its 2006 *Biennial Assessment*, the Board stated the following in its critical issues section of the Community Living Chapter:

"Services to persons with disabilities continue to be administered in highly compartmentalized systems at both the state and local levels. Critical disability services in Virginia are provided by over fifteen distinct state agencies ... The system has so many different sources of information and points of entry and access that it is difficult to understand, monitor, and utilize the services. This is true whether one is an administrator, regulator, individual with disabilities, or provider. Intertwined responsibilities for funding, licensure, eligibility-determination, management, and oversight result in real and perceived conflicts of interest within and between agencies at all government levels.

"There is no over-arching person-centered focus or lifespan organization in the system. Many state agencies have a specific disability constituency determined by diagnosis. Other agencies serve the entire spectrum of disability diagnoses but have a more limited service mandate, e.g., provision of vocational rehabilitation services. In addition, agencies that serve the entire citizenry of Virginia often lack information, knowledge, and experience with regard to the needs of persons with disabilities and do not include them in their planning ...

“The current service system lacks a person-centered focus and a lifespan design. This is most evident regarding persons with developmental disabilities who do not have a concurrent diagnosis of mental retardation despite the implementation of the Developmental Disabilities waiver. Virginia, unlike in other states which have a more inclusive system of services, does not have a state entity designated with responsibility for policy development, service planning, or service provision regarding this population with developmental disabilities ... Unlike individuals with a diagnosis of mental retardation, people with developmental disabilities do not have a “home”, i.e., dedicated funding stream or service system to meet their needs. Thus the service system fails to identify, account for, or plan for the needs of numerous individuals because the nature or severity of their disability does not fall within traditional definitions and the established service system structure. As an example, when important system change initiatives are implemented, such as the current DMHMRSAS Restructuring/Transformation Initiative, the needs of persons with developmental disabilities other than mental retardation are not included as an integral and necessary component of planning, policy, or implementation, thereby significantly impeding progress at the state and local levels for persons who do not have mental retardation.”

For these very reasons, the Board does not believe that establishment of a stand alone autism agency and the creation of additional disability “silos” is the appropriate policy direction for the Commonwealth. The situation in which we find ourselves was, in fact, created by the current service system’s focus on mental retardation and mental illness. The Board is concerned that establishment of a separate agency could result in requests down the line for additional disability specific agencies to address the needs of other underserved populations. Persons with brain injury would be one example.

The Board believes that the focus should be on the manner in which to best deliver the services that people need, not on a disability diagnosis, no matter how urgent the need—and we do believe that there is an urgent need in the area of autism. The establishment of a new agency would not appear to be politically or economically feasible. Further, it could potentially take dollars away from services in order to fund a brand new infrastructure. The Board agrees with the workgroup statement that the Commonwealth needs to “maximize the use of State resources to focus on the provision of services rather than on administration.”

Another consideration is that many children and adults with autism have a concurrent diagnosis of mental retardation. For those who have co-occurring disabilities, the Commonwealth could be establishing competing systems to serve many, albeit certainly not all, of the same individuals. Since a desired goal is and has been to reduce fragmentation and develop a more comprehensive, integrated service system, a separation between mental retardation (which is a developmental disability) and autism/DD would not appear to be a coherent strategy. Should the Commonwealth opt to establish a new agency, the Board would strongly advocate for this to be an all encompassing developmental disabilities agency that includes MR services.

Having said that, there are a number of valid issues that would need to be fully examined in any redesign of DMHMRSAS. We agree with the workgroup statement that this cannot be “business as usual.” There are currently a number of major issues to be addressed: significant gaps in community services, consumer choice in services, the need for staff with proper expertise and training who understand the complexity of autism, and the need for increased public/private partnerships that provide expanded options for families. The Board agrees with and supports the concerns of the workgroup with regard to the need to address the following during any implementation design/discussions:

- Establish a single point of entry and develop an inclusive service system that is not diagnostically focused (eliminate silos of care and fragmentation). This system should involve public/private partnerships and incorporate but not be limited to the CSB system.
- Be based on principles of person centered planning and ensure client/parental choice and client/family directed services as available in the DD waiver.
- Provide or coordinate multiple types of services across an individual’s lifespan to include early diagnosis; early intervention; scientifically-based educational, health care, and therapeutic interventions; and effective transition from secondary school to post-secondary education and/or employment.
- Fund needed services at levels adequate to maintain access to service providers and to reduce lengthy waiting lists.
- Ensure appropriate expertise and training of staff within the agency that will assume responsibility for autism services. Facilitate the development of specialist skills and knowledge pertaining to specific disabilities which enables the use of best practices pertinent to those disabilities in the areas of assessment, medical care, education, behavioral supports, and employment.
- Provide resources for families to learn about scientifically-based therapies.
- Expand the pool of public and private service providers.
- Support residential and community services to allow individuals to function within the community.
- Address the needs of underserved areas of the Commonwealth.

The Board believes that a thoughtful process of programmatic, fiscal, and infrastructure planning is appropriate. We commend the Joint Commission on Health Care’s interest in this issue and the work of Ms. Snead, its Executive Director. Ms. Snead did an outstanding job of working with many constituencies with differing perspectives, ensuring that all voices were heard. It is only through continued collaboration and partnerships that the Commonwealth will move forward in this critically important area. Once again, we appreciate the opportunity for input.

Sincerely,

Heidi Lawyer

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Lisbet Ward

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Cc: The Honorable Marilyn Tavenner, Secretary of Health and Human Resources
Gena Boyle, Governor's Policy Office
James Reinhard, M.D., Commissioner, DMHMRSAS
Patrick Finnerty, Director, DMAS
VBPD Executive Committee