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To:

Members of Behavioral Health Subcommittee  
Joint Commission on Health Care  
900 East Main Street, Suite 3072-E  
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Subject: POAC-NoVA Comment on Proposal for a Home for Autism (Autism Workgroup Proposals)

Dear Members:

Thank you very much for providing the opportunity to comment on the work assembled by the Autism workgroup under the Behavioral Health Subcommittee of the Joint Commission on Health Care.

My name is Chitra Sharathchandra and I am the President of Parents of Autistic Children of Northern Virginia (POAC-NoVA). POAC-NoVA's membership consists of parents of children with autism. A majority of our members have preschool and school-aged children. We have close to 300 families from the Northern Virginia area in our membership. POAC-NoVA's main mission has been to advocate for the use of scientifically based methodologies to educate children with autism. We have been instrumental in convincing Fairfax County Public Schools (FCPS - the largest school district in Virginia) to adopt Applied Behavior Analysis (ABA) principles in teaching children with autism which emphasizes intensive behavioral interventions. We have a strong collaborative relationship with FCPS to ensure that consistency in methodology is maintained between school and home. From our background, you will note two main things (1) we understand autism and (2) we have been successful in building strong bonds with County agencies to ensure that appropriate services are available for our children.

POAC-NoVA has put forward a proposal for a separate agency that would be the home for autism. The new agency, Department of Autism and Low Incidence Developmental Disabilities (DAUTLIDD) is needed in Virginia for the following reasons:



1. To bring focus to autism and ensure that strong supports are available (1) for families who have hope to see their children turn the corner (2) to ensure that there is cost savings for the state in the long run when these children become productive members of society (3) for adults with autism so that they can find employment and lead an independent and productive life in their communities.

Autism is the fastest growing developmental disability in the US. One in every one hundred and fifty children born in the US will have autism. With such an alarming increase in autism numbers, states cannot overlook the impact this will have on costs that society will incur as this population ages. Costs for autism have been clearly documented in a 1998 study published using data from Pennsylvania (“Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism – General Model and Single State Case by John Jacobson, James A. Mulick & Gina Green, Behavioral Interventions). This study demonstrates that close to \$1M can be saved in adult services over the lifetime of an individual with autism when they receive early intensive behavioral interventions. This study gives hope. It gives hope to families that their children have a chance to recover. It gives hope to society that spending on these children early will save money. It gives hope that families will have normal lives. That is why it is imperative that Virginia act immediately to find a home for autism. Virginia is at least 4-5 years behind on autism compared to other states. States such as Wisconsin, Colorado, Indiana and neighboring Maryland have established autism specific waivers. The autism waiver in Maryland was established in the year 2001. States such as New Jersey, Pennsylvania and California have established autism task forces that study and develop policy for autism. None of these exist in Virginia today. So, what happens to the families who hope to see their child recover? What happens when these children grow up and demand adult services? What does Virginia offer these families? Unfortunately - very little to nothing.

2. Implementation of the home for autism under Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) is unacceptable.

Unlike other disability organizations in Virginia, POAC-NoVA disagrees that the right approach to establishing a home for autism is to re-design DMHMRSAS. Re-design of DMHMRSAS will take a long time and people with autism cannot wait for this kind of significant restructuring of a state agency.

Virginia state resources needed for people with autism should not go into fixing an agency. Instead, it needs to be diverted to provide badly needed services. These resources can be well spent if an agency is developed with the right principles from the



very beginning. In engineering, when a new idea is put forward, a prototype is developed and then manufacturing takes place on a large scale. Here we have new ideas for a disability agency but there will be no prototype. Instead an old model will be re-engineered with a band-aid of new ideas to deliver the service. How long will such a model last and how long will resources be diverted to the old model to keep putting new band-aids?

Therefore, instead of re-designing DMHMRSAS, POAC-NoVA proposes the establishment of a new agency called DAUTLIDD. This agency will serve people with autism and lower incidence developmental disabilities (without MR in the initial phase, since this population has a home today). People with dual diagnosis of MR and autism will also be served by DAUTLIDD. DAUTLIDD will be the prototype for a disability agency in Virginia based on the following key principles:

- Be the center of specialist skills and knowledge pertaining to specific disabilities which enables the use of best practices pertinent to those disabilities
  - Be the single point of entry for people with autism and lower incidence developmental disabilities
  - Be based on principles of person centered planning with consumer directed services and choices
  - Separate case management and service delivery entities
  - Allow choice in case management and service delivery
  - Maintain a first come first serve wait list with emergency access slots
3. POAC-NoVA agrees that a single home for developmental disabilities (DD) is needed in Virginia. We just disagree on the path that needs to be taken to reach this objective. Unfortunately, in Virginia we are trying to do two things at the same time. We are trying to re-design DMHMRSAS and trying to bring badly needed services to underserved DD populations. Achieving both these objectives at one time will require a lot of resources. Virginia must make the delivery of services to underserved DD populations a priority. Therefore, POAC-NoVA proposes that creating a single DD agency should be taken in multiple steps with focus given to autism and other lower incidence developmental disabilities first. Our initial proposal on the steps needed to get to a single DD agency are:

Step 1: Create DAUTLIDD and establish services for people with autism and lower incidence developmental disabilities on a small scale (possibly focus on younger children first)

Step 2: Expand DAUTLIDD to include elementary and secondary school children where wrap-around and transition services are defined. Gradually begin restructuring and re-design of DMHMRSAS.



Step 3: Expand DAUTLIDD to include adult services where employment and independent living are key. Continue DMHMRSAS re-design & restructuring

Step 4: Complete integration of DMHMRSAS and DAUTLIDD into a single DD agency and separate Mental Health and Substance Abuse functions.

This approach makes sure that people who need services will not get bogged down by the badly needed restructuring and re-design of DMHMRSAS.

Thanks again for providing the opportunity to work with you on the proposal for a home for autism. We look forward to working together with the Joint Commission on Health Care to come up with the right decisions for our children.

Regards,

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President, POAC-NoVA