

JOINT COMMISSION ON HEALTH CARE

SUMMARY OF PUBLIC COMMENTS:

Autism Workgroup

Updated

Policy Options

Option 1: Take no action.

INTRODUCE JOINT RESOLUTION AND/OR BUDGET AMENDMENT REQUESTING THAT THE SECRETARY OF HHR DEVELOP & REPORT TO CHAIRMEN OF HAC, SFC AND JCHC ON:

Option 2: Implementation Plan to redesign and rename DMHMRSAS to become the primary State agency responsible for serving individuals with autism spectrum disorders. (New responsibility in addition to DMHMRSAS' current responsibilities.)

Option 3: 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.)

Option 4: Implementation Plan to establish a new agency within the HHR Secretariat to be responsible only for serving individuals with autistic spectrum disorders.

Option 5: Implementation Plan to establish a new agency within the HHR Secretariat to be responsible only for serving individuals with developmental disabilities (which would include mental retardation).

Option 6: Implementation Plan to establish a new agency within the HHR Secretariat to be responsible only for serving individuals with developmental disabilities other than mental retardation.

Option 7: Implementation Plan to determine the State agency that should be responsible for serving individuals with autistic spectrum disorders (including whether the agency should serve individuals with any or all developmental disabilities.)

INTRODUCE LEGISLATION AND ACCOMPANYING BUDGET AMENDMENT (LANGUAGE AND FUNDING) TO:

Option 8: Redesign DMHMRSAS to serve individuals with autism spectrum disorders.

Option 9: Redesign DMHMRSAS to serve individuals with developmental disabilities.

Option 10: Establish a new agency to serve individuals with autism spectrum disorders.

Option 11: Establish a new agency to serve individuals with developmental disabilities except for mental retardation.

Option 12: Establish a new agency to serve individuals with developmental disabilities (including mental retardation).

Summary of Comments

A total of 108 individuals and organizations submitted comments (within deadline) in response to the recommendations developed based on the autism work group review. The following table summarizes the number of comments received in support of each of the Policy Options. As shown, no comments were received in support of Options 1, 2, 4, 6, 8, and 10.

Policy Option	Number of Comments in Support
1	0
2	0
3	9 (4 actually support 3 and 9)
4	0
5	2 (1 actually supports 5 and 12)
6	0
7	65
8	0
9	4 (actually support 3 or 9)
10	0
11	31
12	1 (actually supports 5 and 12)
No Specified Option	3

In addition, we received a letter from Senator Potts which read in part: "I have been inundated by opposition with the disability community regarding a decision by the Community Services Boards (CSBs) and a certain advocacy group known as the 'Ability Alliance,' ...wanting to end 'choice' for those being served or on waiting lists for Developmental Disability Waiver. This would turn back the clock for ALL the advocates who have fought so hard and are fighting to keep choice as an option for our loved ones."

The following pages include excerpts from the comments that were submitted.

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.

Comments in Favor of Option 3

Sandy Hermann

The Arc of Virginia

Virginia Association of Community Services Boards

Virginia Association of Community Services Boards – MR Council

Virginia Network of Private Providers

Sandy Hermann of Virginia Beach commented: “I support the recommendation of identifying a home for individuals with developmental disabilities (as federally defined), including autism and mental retardation, which would be responsible for policy development, service planning, and advocating on behalf of this population of individuals. A single point of entry system should be designed for ease into the system. The single point of entry should be prohibited from providing Case Management and Medicaid Waiver services to ensure that conflict of interest does not exist and “true choice” is offered in service provision. Individuals should be able to have a choice in Developmental Disability case management organizations, similar to the current Developmental Disabilities Medicaid Waiver. A fair and equitable first come, first serve wait list, with emergency access to slots, should be maintained for Medicaid Waivers. This home should also include state funding for State services, similar to the current MR system. During the workgroup meetings, DMHMRSAS, was identified as the logical choice to serve as a Developmental Disabilities agency. I would be fully in support of this option as long as the above mentioned items were **included** in the redesigned and renamed DMHMRSAS and it was not just ‘business as usual’ within the agency.”

The Arc of Virginia, Howard Cullum, (Arc President) and Jamie Trosclair (Executive Director) commented on behalf of Arc indicating:

We are confident that the time, energy and resources that have been invested by all stakeholders in this study will help to ensure that individuals with developmental disabilities and their families obtain access to supports needed to live *“A Life Like Yours”* in the community. . . .As an umbrella organization, The Arc of Virginia is committed to increasing equality of opportunity, social inclusion, and independence for individuals with intellectual and developmental disabilities through improving access to adequately funded community-based services.

Individuals with various types of developmental disabilities, family members, and providers of services have shared with us that they have found that the current system, which is driven by “silos” based on a specific diagnosis, creates confusion, barriers to access, and lack of accountability. In an effort to mitigate the need for an individual with a developmental disability and/or family member to navigate a confusing multitude of public and private entities to access support, **The Arc of Virginia concurs with the consensus reached by the workgroup to recommend Option 3. . .** We believe that this solution ensures maximum access to supports and services and is also the most fiscally

responsible way to utilize an existing infrastructure without jeopardizing funding that is desperately needed to increase the availability of supports. Furthermore, DMHMRSAS currently serves individuals with autism who either have a co-occurring intellectual or mental health disability and creating an additional “silo” has the possibility of further hindering access to much needed supports for this population. . . .

Considerable time should be invested in developing a plan that streamlines and improves upon existing service delivery. This plan should take into account the fact that new resources will be necessary to create, establish and implement the infrastructure necessary to appropriately support all people with developmental disabilities. The Arc of Virginia recommends the creation of a position within DMHMRSAS to work with the Secretary on developing this implementation plan.

Virginia Association of Community Services Boards, comments made on behalf of VACSB included:

Option 3 would develop an implementation plan to redesign and rename DMHMRSAS to become the primary state agency responsible for serving individuals with developmental disabilities, including, but not limited to, autism spectrum disorders.

- The VACSB believes that this plan should be comprehensive in identifying roles, responsibilities, funding and capacity requirements, Code changes, and relationships among partnership agencies at the state and local levels, including Education.
- The VACSB supports language that specifies the stakeholder groups who would act in an advisory capacity to the Secretary of Health and Human Resources as the plan is developed. Such stakeholders should include the VACSB, the VNPP, and the Arc of Virginia, among others.
- The VACSB supports language to be added to the Policy Option to fund a position at DMHMRSAS to assist in developing the plan and to facilitate the stakeholders group as issues are considered and solutions found.

For the following reasons, the VACSB is supportive of Policy Option 3:

- DMHMRSAS is a well-respected agency with exceptional leadership and significant expertise in licensure, human rights, contracting, and oversight. Additional infrastructure and expertise would be needed but the current infrastructure provides a good foundation for the most efficient administration of services.
- The State MHMRSAS Board is a policy board, not an advisory board. Its members are responsive to consumers and families and it seeks to develop and implement policies that assist the system in serving consumers and safe-guarding their rights.
- The CSB system, with its network of local public and private providers, is the only statewide service delivery system in the Commonwealth with authorization in the Code of Virginia and accountability to local, state, and federal governments.
- Disability areas are not as distinct as once held. With virtually every disability, there is great potential for depression, anxiety, and other forms of mental illness. DMHMRSAS and CSBs have recognized this and are making efforts to provide transformative services and supports that address the needs and normalcy of the whole person.

Virginia Network of Private Providers, Jennifer G. Fidura commented on behalf of VNPP:

“We would add the following language to Option #3:

- 'The Implementation Plan will due to the Committees listed above on October 1, 2009 with and interim report due on December 1, 2008.'
- 'A budget amendment will be introduced to fund a position at DMHMRSAS in a newly created Office of ASD/DD effective July 1, 2008. The function of this position will be two fold - to assist the Secretary of HHR to develop the Implementation Plan and to meet with all interested stakeholders to ensure their input into the Plan as it is developed.'

We understand the sense of urgency expressed by many of the stakeholders. We recognize, however, that the most serious 'gap' in the system is not the lack of an agency to call home, but the lack of capacity and funding. We will only have one chance to get it right the first time, we need to avail ourselves of that opportunity."

Options 3 and 9

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.

Option 9: [INTRODUCE LEGISLATION AND ACCOMPANYING BUDGET AMENDMENT (LANGUAGE AND FUNDING) TO:] Redesign DMHMRSAS to serve individuals with developmental disabilities.

Comments in Favor of Option 3 or 9

Jean Felts

Carol Skelly

Autism Society of America – Central Virginia Chapter

Virginia Board for People with Disabilities

Jean Felts of Galax commented: "My primary interest is for children with cerebral palsy and other motor impairments, which are defined as developmental disabilities, along with autism and other issues....I feel very strongly that a home agency is needed for these children, and that DMHMRSAS would be the appropriate agency to serve them....I believe that including children with cerebral palsy and other DD issues would not only serve these families better, but would also be cost effective due to the efficiency of the system already in place for MR."

Carol Skelly of Arlington commented: "My opinion is that the most important thing we can do for Virginians with autism is to define eligibility on functional, rather than diagnostic lines. Too often, individuals with autism don't qualify for services because their IQ's are too high, despite the fact that their social and communication deficits make it difficult for them to function in the community. Working toward more functional eligibility and services will require that we serve individuals with developmental disabilities together, and not in separate agencies. It may, of course, also require that Virginia expand certain types of supports, e.g. behavioral supports, which are

inadequately funded in the current MR waiver system. I have two additional concerns about establishing a separate agency for autism. The first is that our families transitioning from the schools are already confused and overwhelmed by the complexity of the service system, so much so that most are incapable of managing their children's entry into the service system. The second is that it is unclear what would happen to individuals who have both autism and mental retardation. Would they be required to give up their existing services under the MR waiver? Or allowed to choose which package of benefits they want?"

Virginia Board for People with Disabilities, Lisbet Ward (Board Chair) and Heidi Lawyer (Executive Director) commented on behalf of the VBPD:

[T]he 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 agenciesThe 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....”

“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”

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.

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.

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.

Option 5: [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 establish a new agency within the HHR Secretariat to be responsible only for serving individuals with developmental disabilities (which would include mental retardation).

Comment in Favor of Option 5

Dana Jackson

Dana Jackson of Roanoke commented: “Using DMHMRSAS as the choice for DD system is not a good fit. DMHMRSAS deals with MR and MH, the ways to work with DD population are quite different. DMHMRSAS and CSB's are not used to nor trained to assist this population. I have worked in the field for 10 years with many CSB's in different areas. They do not give choice nor the different needs for Autism. If any option should be considered it should be Option 5 making sure that all Developmental Disabilities other than MR are included. Otherwise, we end up with an Autism agency then where do the other DD consumers go?”

Options 5 and 12

Option 5: [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 establish a new agency within the HHR Secretariat to be responsible only for serving individuals with developmental disabilities (which would include mental retardation).

Option 12: [INTRODUCE LEGISLATION AND ACCOMPANYING BUDGET AMENDMENT (LANGUAGE AND FUNDING) TO] Establish a new agency to serve individuals with developmental disabilities (including mental retardation).

Comment in Favor of Options 5 and 12

Linda Moore

Linda Moore of Rockville commented: “I agree that individuals with developmental disabilities need a ‘State Agency Home in Virginia.’ I however do not agree with the majority of workgroup members who supported the redesigned DMHMRSAS option. My personal experience with DMHMRSAS and the CSB system have been very disappointing at best. They are a one size fits all service system, with a take it or leave it approach....I am afraid that all the redesigning and renaming would not change the fact that persons with any developmental disability need person – centered services. I just do not see it happening with what I have seen over the last 19 years with the DMHMRSAS/CSB system. Please give individuals with ASD and Developmental Disabilities a HOME OF THEIR OWN not placing them in a foster home situation with DMHMRSAS. My choice is Option 5 and Option 12.”

Option 7: [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 determine the State agency that should be responsible for serving individuals with autistic spectrum disorders (including whether the agency should serve individuals with any or all developmental disabilities).

Comments in Favor of Option 7

Patricia Alf	Marilyn Austin
Pamela Barnes	Randall Beekman
Diane Burr	Mark E. Camporini
Lori Collazzo	James Edward Creamer
Jackie Crownover	Karye Dabney
Danielle Dar Juan	Karina Dar Juan
M. Roxanne Dar Juan	Nannette M. DeLong
Ruby delos Reyes	Stephen Fitz
Allen Ford	Susan Gregory
Wilma Harris	Joseph Harvey
Lorraine Hopcroft	Jayne Hughes
Jill Jacobs	Laura Anne Jacobs
Diane M. Jeffers	Collin Alexander Jacobs
Dana Kavanagh	Keith Kessler
Lynn Leonard	Janet Long
Kathy Maybee	Mervat Mohamed

Tim Moore
Rob Petrie
Ruwani Ranatunga
Dakota Rizzo
Sharon Ross
Kenneth Shaw
Wenyao Shi
Tracy Solomon
Sherif Talaat
M. Tolan
Dagmar Torres
Joshua Wilson

Charlene O'Brien
Sandra Phillips
Sandra Reeves
Lina Roca
Odeyra Santiago
Monique Shaw
Lisa Siegal
Nabil Tallaat
Donna Tohtoh
Mervat Tolan
Anne Tuccillo

4 emails from individuals who did not provide their names

Alliance for Cross-disability Empowerment (ACE)

Blue Ridge Independent Living Center

Disability Action Committee

The Endependence Center

Virginia Association of Centers for Independent Living

Alliance for Cross-disability Empowerment (ACE)

Eric Nordin and Tracy (no last name provided) commented on behalf of the Alliance for Cross-disability Empowerment (ACE):

The Alliance for Cross-disability Empowerment (ACE) is a newly formed disability Coalition in the Commonwealth of Virginia. ACE believes in the concepts of independent living and self-advocacy in a cross-disability environment. In this spirit, the ACE mission is to bring about change by uniting people with disabilities, families of people with disabilities, and professionals who are committed to community-based services for people with disabilities.

In Spring 2007, Virginia's Behavioral health Care Subcommittee of the Joint Commission on Health Care (JCHC) created a work group to identify a primary agency for developing, coordinating and overseeing services for people with Autism. This turned into a broader initiative, more along the lines of "Home for Developmental Disabilities, including Autism Spectrum Disorder and Autism with Mental Retardation" initiative.

Amongst the proposed solutions are some that could have a very serious negative impact on people with Developmental Disabilities (DD), including people with Autism Spectrum Disorder (ASD). ACE's most pressing concerns are:

1. People with DD/ASD will no longer be allowed choice of Case Management agencies.
2. People with DD/ASD and their families could end up completely excluded from the decision-making process about things like how services are delivered; what agencies can provide services; what state organization will run programs; what policies and procedures will be used to administer programs; how long people will wait for services, the amount of funds made available to programs; and how funds are distributed amongst types of recipients.

Given these concerns, ACE cannot support any of the subcommittee's proposed solutions. ACE will ONLY support proposals that reflect the following:

1. Inclusion of people with DD/ASD (and their families, as appropriate) as equal partners with other stakeholders in the planning, decisions-making, and policy/procedure-setting process. This should include active DD Waiver participants, individuals on the DD Waiver waiting list, people with DD/ASD who are not yet old enough to be eligible for the DD Waiver, and individuals with DD/ASD who do not meet the Level of Functioning eligibility requirements.
2. A Waiver service delivery model that prohibits DD Case Management organizations from providing DD Waiver services, except facilitation.
3. A Waiver service delivery model that ensures integrity of existing waiting lists is maintained and that continues to offer a first come, first serve wait list with emergency access slots.
4. A Waiver service delivery model that allows consumers (and/or consumer's families when appropriate) to choose their own Case Management agency. Privately owned and non-profit agencies must be amongst the Case Management agency options.
5. A Waiver service delivery model that allows consumers (and/or consumer's families when appropriate) to choose their own provider agency in all Waiver service categories. Privately-owned and non-profit agencies must be amongst the service provider options.

Ruby delos Reyes of Falls Church commented: "I have a very strong opinion about this subject because I care for a person with Autism Spectrum Disorder. He is a participant in the DD Waiver. I have friends and associates who participate in the MR Waiver. The biggest difference I see between the two Waivers is choice. The DD Waiver offers me choices, and I refuse to have my choices taken away. I cannot agree with any of the proposals that the BHC subcommittee has suggested as possible solutions....I agree with the position identified by the Alliance for Cross-disability Empowerment...."

Pamela Barnes of Northern Virginia, Member of ARC commented: "I am the mother of a child who has been diagnosed Pervasive development Disorder (autism spectrum). I do not want our choices taken away for case management providers or form other DD Waiver providers. I am a member of ARC of Northern Virginia but do not support their proposal if it means having these choices removed...."

Tim Moore of Rockville commented: "I am a 22 year old, self-advocate who has a developmental disability called autism spectrum disorder (ASD)....Having DD Waiver allows me to move into my own place in May of 2005. I have Consumer Directed-Attendant Care, which allows me to employ my own attendant to provide the care I need at the time I need it most....Please remember me as a person as you consider all the options. I want to continue to help decide on the service I need in my IFDDS Waiver Plan of Care. I also want to be able to select my own Case Manager and own attendant care providers. My needs are very individualized to my disability. "

Susan Gregory of Alexandria commented: "I cannot support any of the solutions proposed by the JCHC subcommittee at this time because people with DD/ASD and their

families were not allowed enough involvement in developing the proposed ‘solutions’. Please do not take choices out of the hand of the developmentally disabled and the people who care for them....”

Randall Beekman of Arlington commented: “My son...has waited on the DD Waiver Wait list for nearly five years. He still does not have a slot, but we are close now. We live in Arlington County....autism involves different cognitive impairments than MR, and adults with autism, therefore, have language, sensory, and behavioral deficits that operate differently from MR and require treatment regimens different from adults with MR. Unfortunately, neither the public schools in Virginia, nor the various Virginia CSBs have ever fully recognized or acknowledged that autism is a completely different disability from MR. Instead, they collectively--and very wrongly --assume that the two disabilities are so similar that adults with autism can learn to adapt to the existing range and provision of services which were long ago designed to serve the MR population. In more colloquial language, adults with autism (some school-aged children too) in Virginia are typically treated as if they were square pegs that can simply be pounded into existing round holes. I have battled this attitude many times over the years, but it still seems to prevail in Virginia. In our family, we are very hopeful that once Michael receives a DD Waiver slot we will have more direct input in the decision making regarding the services he will receive and therapies he needs. We hope to work with private sector non-profit entities to administer a grouping of services that will together address Michael's own disability, not someone else's....”

Collin Alexander Jacobs of Woodbridge commented:

My name is Collin. I am almost 15 years old. I have Cerebral Palsy. I use the DD Waive. I live in Woodbridge, Virginia. I attend Freedom High School. I am writing because I learned that a sub-committee will recommend what to do about a home for people with Autism and DD next week. I read all of the options the sub-committee presented on the internet**I don't want any of those options.**

Here is what I want:

1. I want choice.
2. I want to be able to think about what matters to me, talk to different Case Managers, and choose the one I want to use.
3. I want to change and use a new Case Manager if I decide to do that, too.
4. I want to participate, make sure you hear what I have to say about how to make a program that helps people with all kinds of disabilities because you didn't give me a chance to do that yet.

I agree with the ACE position statement....

Virginia Association of Centers for Independent Living, Karen Michalski-Karney, VACIL President commented:

VACIL, supports Option 7....This option would allow the necessary discussion and planning before a determination is made of which agency is appropriate. It is important to first establish what is needed before deciding where the need can be met.

VACIL agrees that persons with autism and other developmental disabilities need a State agency that can assist with planning and advocating for needed services. To meet the needs of persons with autism and other developmental disabilities

appropriately it will be important to ensure that the following issues are addressed:

- People with autism and DD are front and center in the discussion and planning of any combining of services within existing or new State entities.
- If a single point of entry system is used, the entity that is the single point of entry must be separate from any entity that provides case management or any other service. Entry into services and eligibility determination should occur with an entity that is separate from service delivery entities to ensure there is no influence of the choices people must make about their services.
- Increase State funding to ensure that State funded services are available to persons with autism and DD similar to the State funded services now available to persons with mental retardation.
- If the DD Waiver is impacted by the establishment of a State agency for persons with autism and DD the following items are important:
 - Continue to have eligibility determined by an entity separate from case management and service organizations;
 - Continue to allow people to have choice of DD case management organizations;
 - Continue to prohibit DD case management organizations from providing DD Waiver services, except facilitation; and
 - Maintain a first come, first serve wait list with emergency access slots.

These issues and others will need to be discussed and resolved before persons with DD can be expected to support a plan for their services if they are eventually incorporated into any new State structure. If DD services and planning needs are eventually incorporated into the activities of DMHMRSAS, significant changes will need to be made at DMHMRSAS to ensure that persons with DD continue to enjoy the choices they now have and to maintain and expand an appropriate service delivery system. It will be important to assure individuals with DD that their autonomy, choices and control will not be lost in the development of any new State agency structure.

Option 11: [INTRODUCE LEGISLATION AND ACCOMPANYING BUDGET AMENDMENT (LANGUAGE AND FUNDING) TO] Establish a new agency to serve individuals with developmental disabilities except for mental retardation.

Comments in Favor of Option 11

Thomas H. Bland	Gerhard Kraske, MD, MPH
Kathleen Blevins	Carolyn and Michael Ku
Steve L. Blevins, Major, USAF	Jeanne Kuecks
Robert and Donna Budway	James Lafferty
Dawn L. Cassidy	Allen and Amy Lusk
Sean Cassidy	Shannon McGrail
Dr. Afsaneh Chamlou	Johanna Ramos-Boyer

David Cordell
Jane and Bernard De Lury
W. G. and Joyce P. Fendley
Janice Gianopulos
Gregory B. Hagen
Drs. Dennis and Dona Hoilman
Katie Krewatch Hudgins
Leona Hyatt
Beth Jarvis

Christopher M. Rossomondo
Keri and Mike Schoenbrun
Lisa Shaver
Virginia and Henry Woodhead
Guan Xu
Nicole Zupan
An individual identified as a grandparent of
an autistic boy (and an email address)
Parents of Autistic Children – Northern VA

Parents of Autistic Children – Northern VA

Chitra Sharathchandra, President of Parents of Autistic Children – Northern Virginia (POAC-NoVA) commented in support of Option 11 and to name the newly established agency the Department of Autism and Low Incidence Developmental Disabilities (DAUTLIDD). Ms. Sharathchandra's comments in part, indicated:

Parents of Autistic Children of Northern Virginia 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....
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....
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. . . .

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.

Thomas H. Bland of Burke commented: “By creating this department, it will relieve a great deal of burden from the Department of Mental Health, Mental Retardation, and Substance Abuse Services. It would also help *streamline services* for the families of autistic children and the schools that support autistic students. . . .”

Kathleen Blevins of Centreville commented: “DMHMRSAS is saturated with people and struggling to provide services for this wide and disconnected group of people being served in this department. It would be a grave mistake to add a large, rapidly growing, specific population of people with autism to this department. DMHMRSAS is not able to give adequate services in a timely manner, which is of most importance in treating young children for their best chance of independence and for quality of life. Additionally, it will cost more money for the state if these services are not provided to this group earlier in their lives as they will not acquire the skills to be independent or for some, recover. . . . Being assigned to DMHMRSAS will only add stress, heartbreak, and a lower quality of life for my son and family as we are not able to access the appropriate services.”

Drs. Dennis and Dona Hoilman, grandparents of a child who has autism commented: “It would do a grave disservice to autistic children to add the responsibility for autism services to DMHMRSAS, which is already overloaded and struggling. Virginia’s status as number 48 in the nation in autism funding is shameful enough. Please help to address this growing epidemic by recommending the approval of the POAC-NoVA proposal. Burying responsibility for autism in DMHMRSAS will only prevent or delay the efficient and effective delivery of services to children who really need them.”

Beth Jarvis of Alexandria commented: “As a family that has been on the waiting list for the DD Waiver for several years, we are growing impatient with the bureaucratic quagmire that families currently encounter when trying to access resources for autism in the state of Virginia. Putting autism resources under the DMHMRSAS umbrella is inefficient and stretches an already overburdened agency. . . . Autism is not going away and is something our state needs to do a better job of acknowledging and providing resources for. Creating a separate agency, DAUTLIDD, to oversee this population of citizens is the answer. Virginia is accountable to our citizens with autism and paying upfront and now

by being proactive and innovative will ultimately be more fiscally responsible than paying later when these very citizens will require a lifetime of expensive, adult services.”

James Lafferty of Alexandria commented:

The Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) is already overwhelmed and is, according to one DMHMRSAS official, undergoing a reorganization process at present in an attempt to become more “consumer friendly.”

The working group’s recommendation that autism should be added to the DMHMRSAS portfolio and then the agency should be re-named, reformulated, etc. to meet its responsibilities to Virginia citizens with Autism is a "cart before the horse" approach. A detailed plan of action with an appropriate sense of the magnitude and urgency of the autism epidemic should be carefully researched and constructed and then an agency which can execute the plan successfully should be identified or created.

Entrusting my child and other developmentally disabled citizens of Virginia to the confused and ineffective management of DMHMRSAS and then after-the-fact rushing to the policy drawing board to write the plan for the future of these citizens is “leaping before you look.”

How many years are our children expected to linger in the shadows of DMHMRSAS while this agency makes plans to right itself?

DAUTLIDD offers an agency which would focus on autism and developmental disabilities in an easily monitored and transparent environment. Autism has a relatively compact window of opportunity for therapies which can undo the effects of the disorder. This sets it apart from other disorders which require a more long-term approach. . . .

Please take the methodical and sensible approach of formulating a plan of action and then securing the resources necessary to completing the task.

Virginia and Henry Woodhead of Alexandria commented: “We are grandparents of a grandson with autism. Our family has had great trouble getting services for this child through public sources. He is now 8 years old, and had he had the therapies he needed at a younger age, would certainly be more recovered than he is right now. We have every expectation that he will recover his ability to function in society without becoming a burden, but it will not be because he was helped by the public sources. . . . We are staunchly in favor the POAC-NoVA (Parents of Autistic Children, Northern Virginia) option which would establish a new agency called DAUTLIDD to ensure that funding for the fight against autism and the services established to assist the parents of autistic children are transparent and easily accessed. . . . We cannot afford the delays, long waiting periods and other inefficiencies which plague a wide range of DMHMRSAS programs. Autistic children should not be held hostage while DMHMRSAS tries to recreate itself and get organized.”

Nicole Zupan of Burke commented: “I am very much in favor of POAC-NoVA's recommendation to establish the Dept. of Autism and Low Incidence

Developmental Disabilities (DAUTLIDD). The creation of this agency would ensure transparency in funding the fight against autism, and in the services needed to assist parents of autistic children.”

Comments without Specifying Support of Any Option

Kyung Jun

Bill McGrail

Tidewater Autism Society of America

Tidewater Autism Society of America

JoAnna Bryant, President of the Tidewater Autism Society of America commented regarding implementation concerns. Ms. Bryant’s comments indicated:

The Autism Society of America (ASA) is the leading voice and resource of the entire autism community in education, advocacy, services, research and support. . . .

As a representative of the Tidewater Autism Society of America, I had the opportunity to participate in the Autism Work Group focusing on recommending an appropriate “home” for championing ASD-related services. Based on that participation, I am writing to ensure that family voices are heard. As family members and stakeholders, we are very invested in the potential structure of the service delivery system of which ever state agency is chosen. It is imperative that families have choice in service providers, disallowing case managers to act as providers, fair and equitable wait list system (number driven), with a separate entity to determine eligibility. This entity should not be allowed to provide services.

It was evident by the discussions held during our meetings that the needs of families are important to the work you are doing. Not all agencies well understand the importance of a service delivery that is consumer driven. The issues raised by families during the meetings should be given much more consideration. We appreciate the leadership and sensitivity you have presented during this process.