REPORT OF THE
JOINT COMMISSION ON HEALTH CARE

Lead Agency to Serve Individuals with Autism Spectrum Disorders

TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA

REPORT DOCUMENT NO. 147

COMMONWEALTH OF VIRGINIA
RICHMOND
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Code of Virginia § 30-168.

The Joint Commission on Health Care (the Commission) is established in the legislative branch of state government. The purpose of the Commission is to study, report and make recommendations on all areas of health care provision, regulation, insurance, liability, licensing, and delivery of services. In so doing, the Commission shall endeavor to ensure that the Commonwealth as provider, financier, and regulator adopts the most cost-effective and efficacious means of delivery of health care services so that the greatest number of Virginians receive quality health care. Further, the Commission shall encourage the development of uniform policies and services to ensure the availability of quality, affordable and accessible health services and provide a forum for continuing the review and study of programs and services.

The Commission may make recommendations and coordinate the proposals and recommendations of all commissions and agencies as to legislation affecting the provision and delivery of health care.

For the purposes of this chapter, "health care" shall include behavioral health care.

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The Honorable Stephen H. Martin

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Preface

"Autism spectrum disorders (ASDs) are a group of developmental disabilities defined by significant impairments in social interaction and communication and the presence of unusual behaviors and interests….The thinking and learning abilities of people with ASDs can vary – from gifted to severely challenged. ASD begins before the age of 3 and lasts throughout a person's life. It occurs in all racial, ethnic, and socioeconomic groups and is four times more likely to occur in boys than girls."
(**Source:** *Autism Information Center*, Centers for Disease Control and Prevention Website.)

Estimates regarding the prevalence of ASD have increased exponentially in recent years with the current estimate being 1 child in every 150 in the United States. The Commonwealth of Virginia, like many states, is struggling to address the ever-increasing need for educational and support services for children and adults with ASDs.

The Behavioral Health Care Subcommittee of the Joint Commission on Health Care (JCHC) began its review of issues related to autism spectrum disorders in 2005. The Subcommittee learned of the significant educational and support needs of persons with ASDs and the critical need for one State agency to have primary responsibility for planning and service provision. Legislation and budget amendments, introduced on behalf of JCHC, sought to address some of the most pressing needs. HJR 96 and SJR 125 (2006) were identical resolutions which asked: (1) the Department of Education to continue to implement initiatives to strengthen teacher qualifications related to the needs of children with ASDs; and (2) the Department of Mental Health, Mental Retardation and Substance Abuse Services to assist in expanding "training opportunities that include approaches specifically addressing the needs of children with autism spectrum disorders…." HJR 96 and SJR 125 were adopted unanimously by the 2006 General Assembly.

During the 2008 Session, JCHC introduced a budget amendment requesting that the Secretary of Health and Human Resources develop and report on an Implementation Plan to determine the State agency that should be responsible for serving individuals with autism spectrum disorders. Although the suggested language was not included in the approved budget, a letter was sent by the Chairman of JCHC asking the Secretary of Health and Human Resources to develop and report on an Implementation Plan.

On behalf of the Joint Commission and staff, I would like to thank the consumers, families, advocates, and public and private representatives, who are too numerous to enumerate, for their many valuable contributions to this review.

Kim Snead
Executive Director
May 2008

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Lead Agency to Serve Individuals with Autism Spectrum Disorders

Executive Summary

Background

"Autism spectrum disorders (ASDs) are a group of developmental disabilities defined by significant impairments in social interaction and communication and the presence of unusual behaviors and interests…. The thinking and learning abilities of people with ASDs can vary – from gifted to severely challenged ASD begins before the age of 3 and lasts throughout a person's life. It occurs in all racial, ethnic, and socioeconomic groups and is four times more likely to occur in boys than girls." (**Source:** *Autism Information Center*, Centers for Disease Control and Prevention Website.)

This is the third year that the Behavioral Health Care (BHC) Subcommittee of the Joint Commission on Health Care has reviewed a subject related to ASDs.

> Estimates of the prevalence of autism (and later of ASD) have increased exponentially. For decades the prevalence was thought to be 4 to 5 cases per 10,000 children in the U.S. However, a 2007 study by the Centers for Disease Control and Prevention resulted in a revised estimate that approximately 1 child in every 150 in the U.S. will have an ASD. A child is diagnosed with autism every <u>20 minutes</u> in the U.S.
> **Source**: *Autism Information Center*, Centers for Disease Control and Prevention website.

2005 Review by the Behavioral Health Care Subcommittee. The BHC Subcommittee initiated a review in 2005 related to educational services for children with ASDs. The Subcommittee heard the findings of the study, *Services Available for Individuals with Autism and Pervasive Developmental Disorders* completed in 2001 by the Virginia Institute for Developmental Disabilities at Virginia Commonwealth University (VCU). The study, which was requested by the Department of Education (DOE), found:

- Although there was a steady increase in the number of children with ASDs served in Virginia's school systems, few teaching "professionals indicated they received adequate preparation to teach children with autism during their preservice training program and many indicated limited satisfaction with both their access to inservice training and the usefulness of the training they received."
- In addition, special education administrators cited such barriers to employing qualified teachers as "the existence of a teacher shortage in special education (84 percent), few teachers being trained to work with this population (80 percent), and few teachers being interested in working with this population (47 percent).

Subsequent to the VCU study, a number of ASD-specific training opportunities were developed. These opportunities included an online program through George Mason University, graduate-level courses offered in a number of Virginia universities, and the DOE-sponsored Train the Trainer program. Train the Trainer involves six days of initial training and two days of follow-up that will be provided for "teams" of representatives from each school division. In addition, the Virginia Autism Council (an interagency group funded by DOE) has developed competencies to guide training of professionals and paraprofessionals who work with individuals with autism.

During the 2006 General Assembly Session, House Joint Resolution 96 and Senate Joint Resolution 125 were introduced on behalf of the Joint Commission on Health Care (JCHC). The identical resolutions asked the Board and Department of Education to continue to implement initiatives to strengthen teacher qualifications related to the needs of children with ASDs. The resolutions also asked the Department of Mental Health, Mental Retardation and Substance Abuse Services to assist in expanding "training opportunities that include approaches specifically addressing the needs of children with autism spectrum disorders…."HJR 96 and SJR 125 were adopted unanimously by the General Assembly.

2006 Review by the Behavioral Health Care Subcommittee. The BHC Subcommittee voted to continue its review of educational and support services for ASDs in its 2006 work plan. Susan Williams, Ph.D. of VCU's Virginia Treatment Center for Children, Dr. Patricia Abrams of DOE, and Carol Schall, Ph.D. of the Virginia Autism Resource Center gave presentations regarding resources in Virginia. The need for a lead State agency for ASD was identified as a significant issue as there is no centralized responsibility for or coordination of policy and services across the lifespan for individuals with ASD in Virginia.

During the 2007 General Assembly Session, a budget amendment of $288,500 for VCU was introduced on behalf of JCHC. The budget amendment was designed to support a variety of training and technical assistance activities related to working with individuals with ASD. The requested funding was not included in the approved State budget.

2007 Review by the Behavioral Health Care Subcommittee

The BHC Subcommittee voted to convene a work group to develop a consensus regarding which State agency should be established or designated as the lead agency for ASD services. During the 2007 Session, HR 60 (Shannon and Nutter) had commended JCHC on "its study of autism and its efforts to recommend a state agency to be designated as the lead agency on autism services for the Commonwealth." In addition, the Virginia Disability Commission sent a letter endorsing the BHC Subcommittee's efforts.

The issue of designating an agency to be the State "home" for autism has been raised by a number of groups. The absence of a State home has meant that no one agency has the responsibility or legislative mandate to develop policy, to plan and coordinate service delivery, to request funding or to undertake strategic planning for the needs of the ever-increasing number of Virginians with an ASD.

Consideration of Lead Agency for ASD or for Developmental Disability Services. ASD is a developmental disability. The Federal Developmental Disabilities Act, defines "the term 'developmental disability' as a severe, chronic disability of an individual that –

- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (ii) is manifested before the individual attains age 22;
- (iii) is likely to continue indefinitely;
- (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:
    - (I) Self-care
    - (II) Receptive and expressive language
    - (III) Learning
    - (IV) Mobility
    - (V) Self-direction
    - (VI) Capacity for independent living
    - (VII) Economic self-sufficiency; and
- (v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

(B) INFANTS AND YOUNG CHILDREN. – An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in clauses (i) through (v) of subparagraph (A) if the individual, without services and supports, has a high probability of meeting those criteria later in life."

In addition to ASD, the following conditions are considered to be a developmental disability (DD) including:

Mental retardation
Brain injury (before age 22)
Cerebral palsy
Fetal alcohol syndrome
Muscular dystrophy
Spina bifida.

Work Group Activities. JCHC staff convened work group meetings on June 26th, July 13th, August 20th and October 29th. Staff endeavored to be inclusive and approximately 80 identified parties were invited to attend and participate.

However, these were public meetings and everyone who attended or participated by conference call was invited to participate as a work group member. More than 30 individuals attended each meeting representing a wide range of stakeholders including:

- Family members and advocacy association representatives
- Public and private sector providers
- Executive and legislative branch representatives and staff.

The workgroup discussed a number of issues as being important to consider in deciding on and establishing an agency, such as to:

- Establish a single point of entry and develop an inclusive service system that is not diagnostically focused (eliminate silos of care and fragmentation).
- Ensure parental/client choice and family/client directed services.
- Provide or coordinate multiple types of services across the 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.
- Ensure appropriate expertise and training of staff related to developmental disabilities within the agency that will assume the new responsibilities.
- 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.
- Provide training for professionals (physicians and day care providers were mentioned specifically) to recognize the need to screen for developmental disabilities.
- Address workforce issues by:
    - Providing incentives for colleges and universities to provide educational opportunities and for students via grants, scholarships, and loan repayments.
    - Defining standards and compensation for highly-qualified teachers, service providers, and professionals.
    - Addressing the needs of underserved areas of the Commonwealth.
    - Maximizing the use of State resources to focus on the provision of services rather than on administration.

During the July 13th meeting, a tentative, initial consensus was reached to redesign and rename DMHMRSAS to serve as the lead agency for developmental disabilities (which would include ASD, mental retardation and the other developmental disabilities as defined in federal law).

- However, the parties involved in reaching consensus did not adequately represent the interests of individuals with ASD or other developmental disabilities. This was demonstrated in the distribution of public comments that were received on the proposed policy options.

Consequently, a follow-up meeting was held on October 29 and after much discussion, a vote of the individuals who attended was taken and individuals who participated by conference call were asked to send an email indicating their vote. **Twenty-four of the 34 individuals in attendance and 7 conference call participants voted in favor or Option 7**. (The other individuals in attendance refrained from voting.)

- A follow-up email was sent out asking anyone preferring an Option other than Option 7 to respond. **No "final" responses were received, other than additional responses in favor of Option 7.**

Policy Options

Option 1: Take no action.

Introduce Joint Resolution and/or Budget Amendment Requesting that the Secretary of Health and Human Resources (HHR) Develop and Report to Chairmen of the House Appropriations Committee, Senate Finance Committee 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 autism 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:** ~~Introduce Joint Resolution and/or~~ By letter of the Chairman and by budget amendment request that the Secretary of HHR develop and report to Chairmen of HAC, SFC and JCHC on an Implementation Plan to determine the State agency that should be responsible for serving individuals with autism 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).

Public Comments on Policy Options

A total of 107 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

Excepts from Public Comments

Senator H. Russell Potts, Jr. commented 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."

Comments in Support of Option 3

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 Submitted 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 exit 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 Are 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 <u>all</u> 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:
"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."

<u>Comments in Support of Options 3 and 9</u>

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 Submitted in Favor of Options 3 and 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 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….

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."

Comments in Support of Option 5

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 Submitted 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?"

Comments in Support of 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 Submitted 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."

Comments in Support of Option 7

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 Submitted 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
Charlene O'Brien
Rob Petrie
Sandra Phillips
Ruwani Ranatunga
Sandra Reeves
Dakota Rizzo
Lina Roca
Sharon Ross
Odeyra Santiago
Kenneth Shaw
Monique Shaw
Wenyao Shi
Lisa Siegal
Tracy Solomon
Nabil Tallaat
Sherif Talaat
Donna Tohtoh
M. Tolan
Mervat Tolan
Dagmar Torres
Anne Tuccillo
Joshua Wilson
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."

Comments in Support of Option 11

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 Submitted in Favor of Option 11

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

JCHC Staff for this Report

Kim Snead
Executive Director

Behavioral Health Care Subcommittee

Joint Commission on Health Care

Autism Work Group

Activities and Recommendations

Kim Snead
Executive Director
September 19, 2007

Background

Background

"Autism spectrum disorders (ASDs) are a group of developmental disabilities defined by significant impairments in social interaction and communication and the presence of unusual behaviors and interests. Many people with ASDs also have unusual ways of learning, paying attention, or reacting to different sensations. The thinking and learning abilities of people with ASDs can vary – from gifted to severely challenged. ASD begins before the age of 3 and lasts throughout a person's life. It occurs in all racial, ethnic, and socioeconomic groups and is four times more likely to occur in boys than girls."

Source: *Autism Information Center*, Centers for Disease Control and Prevention Website.

Background

- Estimates regarding the prevalence of autism (and later of ASD) have increased exponentially
  - For decades the prevalence was thought to be 4 to 5 cases per 10,000 children in the US.
  - In 2007, a CDC study resulted in a revised estimate of approximately 1 child in every 150 in the US will have an ASD.
  - A child is diagnosed with autism every 20 minutes in the US.

Background

- JCHC's Behavioral Health Care (BHC) Subcommittee has studied issues related to autism for the past 2 years and legislation and budget amendments were introduced on behalf of JCHC.
  - During the 2006 Session HJ 96/SJ 125 were introduced and approved.
    - The Board and Department of Education and the Board and Department of Mental Health, Mental Retardation and Substance Abuse Services were encouraged to improve the education and treatment of individuals with ASD.
  - During the 2007 Session, a budget amendment was introduced but not included in the approved budget.
    - Would have provided $288,500 GFs for VCU to support workforce development and to disseminate basic instructional strategies related to working with individuals with ASD.

Background

- The BHC Subcommittee voted to continue its review related to autism in its 2007 work plan and convene a work group to recommend a primary agency for developing, coordinating, and overseeing autism services.
- No one State agency has the responsibility or legislative mandate to develop policy, plan and coordinate service delivery, request funding, or undertake long-range strategic planning for the needs of all of the ever-increasing number of Virginians with an ASD.

JCHC's Subcommittee study was referenced by others:

- Delegate McQuigg sent a letter on behalf of the VA Disability Commission endorsing the BHC Subcommittee work plan.

- House Resolution 60 (Delegate Shannon and Delegate Nutter) commended JCHC on "its study of autism and its efforts to recommend a state agency to be designated as the lead agency on autism services for the Commonwealth."

Autism Work Group Activities & Process

Autism Work Group Activities & Process

Work group was convened

Everyone who attended or called in by conference call was invited to participate as a work group member.

Meetings were held on June 26th, July 13th, and August 20th.

Approximately 80 interested parties were invited to attend and participate in meetings

- Endeavored to be inclusive in identifying potential work group participants.

More than 30 individuals attended each meeting representing a wide range of stakeholders including:

- Family members and advocacy association representatives
- Public and private sector providers
- Executive and legislative branch representatives and staff including Delegate Shannon.

Concerns of Work Group Members

Issues discussed as being important to consider in deciding on and establishing an agency

- Establish a single point of entry and develop an inclusive service system that is not diagnostically focused (eliminate silos of care and fragmentation).
- Ensure parental/client choice and family/client directed services.
- Provide or coordinate multiple types of services across the 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.
- Ensure appropriate expertise and training of staff related to developmental disabilities within the agency that will assume the new responsibilities.
- 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.
- Provide training for professionals (physicians and day care providers were mentioned specifically) to recognize the need to screen for developmental disabilities.

Concerns of Work Group Members

Address workforce issues:

- Provide incentives for colleges and universities to provide educational opportunities and for students via grants, scholarships, and loan repayments.
- Define standards and compensation for highly-qualified teachers, service providers, and professionals.
- Address the needs of underserved areas of the Commonwealth.

- Maximize the use of State resources to focus on the provision of services rather than on administration.

Consideration of Agency for ASD or for DD Services

The Federal Developmental Disabilities Act, states “the term ‘developmental disability’ means a severe, chronic disability of an individual that–

(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;

(ii) is manifested before the individual attains age 22;

(iii) is likely to continue indefinitely;

(iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:

(I) Self-care.

(II) Receptive and expressive language.

(III) Learning.

(IV) Mobility.

(V) Self-direction.

(VI) Capacity for independent living.

(VII) Economic self-sufficiency; and

Consideration of Agency for ASD or for DD Services

(v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

(B) INFANTS AND YOUNG CHILDREN. -An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in clauses (i) through (v) of subparagraph (A) if the individual, without services and supports, has a high probability of meeting those criteria later in life.”

Examples of conditions considered to be a developmental disability (DD) include:

- Autism spectrum disorders
- Mental retardation
- Brain injury (before age 22)
- Cerebral palsy
- Fetal alcohol syndrome
- Muscular dystrophy
- Spina bifida.

Options for a State Agency Home in Virginia

1. Redesign and rename DMHMRSAS to serve persons with ASD.
2. Redesign and rename DMHMRSAS to serve persons with the more inclusive range of "developmental disabilities" which includes ASD and mental retardation.
3. Establish a new agency within the HHR Secretariat to serve persons with ASD.
4. Establish a new agency within the HHR Secretariat to serve persons with developmental disabilities except mental retardation which would continue to be served by DMHMRSAS.
5. Establish a new agency within the HHR Secretariat to serve persons with the more inclusive range of "developmental disabilities" which includes ASD and mental retardation.

Support for a Redesigned DMHMRSAS Option

- The majority of work group members supported the Option for the Secretary of Health and Human Resources to complete a feasibility assessment of expanding, redesigning and renaming DMHMRSAS to serve persons with any developmental disability (in addition to current clients).
  - Indicated a desire to provide services to address developmental disabilities rather than just for ASD in order to reduce administrative barriers and "silos" that result when services are based on conditions and diagnoses rather than according to individuals' actual needs.

Concepts Underlying Option for Redesigned DMHMRSAS

The consensus of most work group members included:

DMHMRSAS is a logical choice for developing a coordinated DD system because of experience in providing services to persons with mental retardation.

However, the redesign should not result in simply an add on to the current agency structure or "business as usual" but instead should:

Ensure staff expertise by employing additional staff (who are collectively) skilled in working with all of the developmental disabilities.

Assure recipient and caregiver choice in the services received.

Concepts Underlying Option for Redesigned DMHMRSAS

The Secretary of Health and Human Resources would be asked to involve:

- All appropriate stakeholders
- Consumers
- Family members
- Advocacy associations
- Public and private providers, and
- State officials and staff in:
  - determining the demographics and numbers of persons to be served,
  - identifying the legislative and regulatory changes and the funding required, and
  - establishing a detailed work plan and benchmarks for implementation.

Implementation Concerns about a Redesigned DMHMRSAS

Implementation concerns to be addressed by the work group include:

- MR system has a single point of entry through the CSB system which serves persons with MR.
  - Although there is no single point of entry for DD/ASD services, a number of DD/ASD work group members indicated their support for establishing a public-private partnership that incorporates but is not limited to the current CSB system.
  - In addition, the work group members asked that the concerns listed on Slides 9 and 10 be considered in establishing a State home for developmental disabilities.

Slides from Parents of Autistic Children of Northern Virginia

(Slides 20-25)

Additional Concerns of Parents of Autistic Children – Northern Virginia

- Issues discussed as being important to consider in deciding on and establishing a separate agency:
    - Address the need for urgency of services for people with autism in Virginia with a plan to dive-in and focus on autism immediately.
    - Ensure that there is a single minded focus and rapid delivery of services which may be hampered if the function resides in an existing agency
    - Agency structure should allow for efficient inter-workings and high visibility with other Virginia agencies
    - Address the need to monitor and track autism rates
    - Address the need to track efficacy of services on autism recovery rates

Source: Slide submitted by Parents of Autistic Children – Northern Virginia.

Department of AUTism and Lower Incidence Developmental Disabilities (DAUTLIDD) Option

- Establish DAUTLIDD as an independent and separate entity to demonstrate the high priority that Virginia places on autism
- Establish DAUTLIDD as a specialist agency on autism that other state agencies seek for autism advice
- DAUTLIDD, with a single-minded focus on autism, will
    - enable leadership that is uniquely suited to meet the needs of the autism community in expertise and experience
    - create a service delivery system based on scientifically based methodologies
- DAUTLIDD can start small and can prototype a model for delivery of services for people with autism and be gradually scaled up
- DAUTLIDD will put in place processes to track efficacy of delivery of services for people with autism
- DAUTLIDD will develop strong partnerships with DMAS, DRS, VBPD and VDOE to communicate best practices pertaining to autism in the areas of education, employment and independent living
- Substantial amount of investment is expected in the area of autism research especially research to determine why autism occurs. DAUTLIDD will make strong connections with national medical agencies to communicate new research findings to the medical community in Virginia so interventions can reach people with autism quickly

Source: Slide submitted by Parents of Autistic Children – Northern Virginia.

Department of AUTism and Lower Incidence Developmental Disabilities (DAUTLIDD) Option (continued)

- Virginia has the opportunity to use DAUTLIDD as the model agency for people with disabilities. This model will :
  - 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
- Virginia is already very late in providing a home for autism and placing the home AFTER redesigning DMHMRSAS will further delay the delivery of much-needed services to people with autism

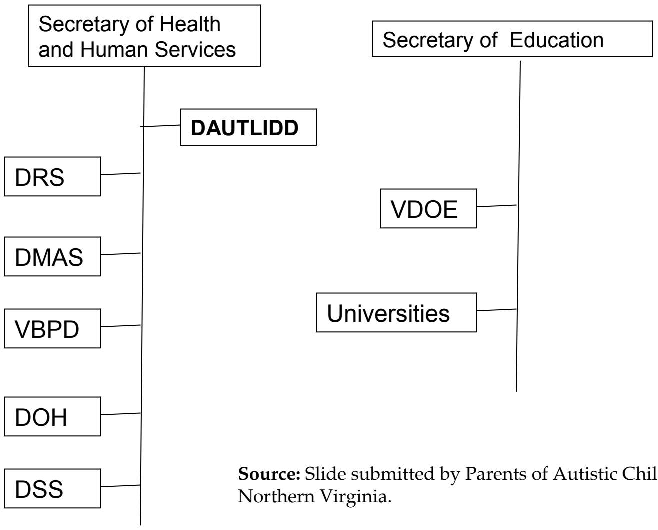
Source: Slide submitted by Parents of Autistic Children – Northern Virginia.

Department of AUTism and Lower Incidence Developmental Disabilities (DAUTLDD) Option (continued)

- Individuals with dual diagnosis (Autism and MR) will be served by DAUTLDD as a majority or all these individuals have autism and have received MR diagnosis for one of the following reasons (1) state agency's inability to diagnose autism (2) school system's inability to diagnose autism or (3) lack of knowledge about autism when child was young
- Lower incidence development disabilities (other than MR) will also be served by DAUTLIDD based on principles used to serve people with autism. This is to ensure that there is no delay in getting services to these communities who continue to be underserved as well
- DAUTLIDD allows the development of specialist skills and knowledge pertaining to specific disabilities which enables the use of best practices pertinent to those disabilities

Source: Slide submitted by Parents of Autistic Children – Northern Virginia.

DAUTLIDD Structure & Partners



Secretary of Health and Human Services

DAUTLIDD

DRS

DMAS

VBPD

DOH

DSS

Secretary of Education

VDOE

Universities

Source: Slide submitted by Parents of Autistic Children – Northern Virginia.

Policy Options

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.)

Policy Options

Introduce Joint Resolution and/or Budget Amendment Requesting that the Secretary of HHR Develop & Report to Chairmen of HAC, SFC and JCHC on:

Option 4: Implementation Plan to establish a new agency within the HHR Secretariat to be responsible only for serving individuals with autism 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 autism spectrum disorders (including whether the agency should serve individuals with any or all developmental disabilities).

Policy Options

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).

Public Comments

- Written public comments on the proposed options may be submitted to JCHC by close of business on October 10, 2007. Comments may be submitted via:
  - E-mail (sareid@leg.state.va.us)
  - Facsimile (804/786-5538) or
  - Mail: Joint Commission on Health Care
    P.O. Box 1322
    Richmond, Virginia 23218

- Comments will be summarized and presented to JCHC during its October 17th meeting.

Appendix A

2006 SESSION

ENROLLED

HOUSE JOINT RESOLUTION NO. 96

Encouraging the Board and Department of Education and the Board and Department of Mental Health, Mental Retardation and Substance Abuse Services and other relevant entities to take certain actions to improve the education and treatment of individuals with autism spectrum disorders.

Agreed to by the House of Delegates, March 2, 2006
Agreed to by the Senate, February 28, 2006

WHEREAS, autism spectrum disorders (ASDs), as characterized by the National Institute of Mental Health (NIMH), cause "varying degrees of impairment in communication skills, social interactions, and restricted, repetitive and stereotypical patterns of behavior"; and

WHEREAS, most often diagnosed in early childhood, ASDs range from severe (autistic disorder) "through pervasive development disorder not otherwise specified (PDD-NOS), to a much milder form, Asperger syndrome"; and

WHEREAS, as noted on the NIMH website, "[t]there is no single best treatment package for all children with ASD"; and

WHEREAS, while noting that autism was only added to special education in 1991, the Centers for Disease Control and Prevention (CDC) acknowledges that the number of children classified as having ASD for purposes of special education services has increased "six-fold" from 1994 to 2003 and also recognizes that "it is clear that more children than ever before are being classified as having an Autism Spectrum Disorder"; and

WHEREAS, the CDC prevalence rates for ASDs have been summarized as "between 1 in 500 (2/1,000) to 1 in 166 children (6/1,000)"; and

WHEREAS, a 2001 study entitled Services Available for Individuals with Autism and Pervasive‑Developmental Disorders found "[f]ew professionals indicated that they received adequate preparation to teach children with autism during their preservice training programs and many indicated limited satisfaction with both their access to inservice training and the usefulness of the training they received"; and

WHEREAS, the 2001 study also indicated that there is a teacher shortage in special education; therefore, since that time, the Department of Education has provided additional training opportunities to teachers serving students with disabilities such as autism spectrum disorders through Training and Technical Assistance Centers that are located in the eight superintendent's regions around the Commonwealth; and

WHEREAS, in recent years, some additional training opportunities for teachers of children with ASDs have become available, such as the Department of Education's Autism Priority Project Teams, George Mason University's online training program, and various courses offered by Virginia Commonwealth University, Regent University, and James Madison University as well as other Virginia institutions of higher education; and

WHEREAS, the Behavioral Health Care Subcommittee of the Joint Commission on Health Care has received presentations from school division representatives relating to the challenges of serving children with ASDs and did unanimously approve on November 10, 2005, the introduction of this resolution and the continuation of the study of autism in its 2006 workplan; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Board and Department of Education and the Board and Department of Mental Health, Mental Retardation and Substance Abuse Services and other relevant entities be encouraged to take certain actions to improve the education and treatment of individuals with autism spectrum disorders. During the regulatory review and public comment periods for the proposed revisions to the Regulations Governing the Review and Approval of Education Programs in Virginia and the Virginia Licensure Regulations for School Personnel, the Board and Department of Education are urged to continue to implement initiatives designed to strengthen teacher qualifications, to include preservice and inservice professional development opportunities relating to the effective treatment of autism spectrum disorders, and to consider the treatment of autism spectrum disorders. Further, the Board and Department of Education are urged to examine appropriate educational placements considering the individualized educational plans of autistic students, the effects of mainstreaming, and the feasibility of alternative placements in public and private schools having qualified staff and adequate facilities. Finally, the Board and Department of Mental Health, Mental Retardation and Substance Abuse Services and other relevant entities are urged to continue to expand training opportunities that include approaches specifically addressing the needs of children with autism spectrum disorders; and, be it

RESOLVED FURTHER, That the Clerk of the House of Delegates transmit a copy of this resolution to the President of the Board of Education and the Commissioner of the Department of Mental Health, Mental Retardation and Substance Abuse Services, requesting that they further disseminate copies of this resolution to their respective constituents so that they may be apprised of the sense of the General Assembly of Virginia in this matter.

Appendix B

2006 SESSION

ENROLLED

SENATE JOINT RESOLUTION NO. 125

Encouraging the Board and Department of Education and the Board and Department of Mental Health, Mental Retardation and Substance Abuse Services and other relevant entities to take certain actions to improve the education and treatment of individuals with autism spectrum disorders.

Agreed to by the Senate, February 8, 2006
Agreed to by the House of Delegates, March 6, 2006

WHEREAS, autism spectrum disorders (ASDs), as characterized by the National Institute of Mental Health (NIMH), cause "varying degrees of impairment in communication skills, social interactions, and restricted, repetitive and stereotypical patterns of behavior"; and

WHEREAS, most often diagnosed in early childhood, ASDs range from severe (autistic disorder) "through pervasive development disorder not otherwise specified (PDD-NOS), to a much milder form, Asperger syndrome"; and

WHEREAS, as noted on the NIMH website, "[t]here is no single best treatment package for all children with ASD"; and

WHEREAS, while noting that autism was only added to special education in 1991, the Centers for Disease Control and Prevention (CDC) acknowledges that the number of children classified as having ASD for purposes of special education services has increased "six-fold" from 1994 to 2003 and also recognizes that "it is clear that more children than ever before are being classified as having an Autism Spectrum Disorder"; and

WHEREAS, the CDC prevalence rates for ASDs have been summarized as "between 1 in 500 (2/1,000) to 1 in 166 children (6/1,000)"; and

WHEREAS, a 2001 study entitled *Services Available for Individuals with Autism and Pervasive Developmental Disorders* found "[f]ew professionals indicated that they received adequate preparation to teach children with autism during their preservice training programs and many indicated limited satisfaction with both their access to inservice training and the usefulness of the training they received"; and

WHEREAS, the 2001 study also indicated that there is a teacher shortage in special education; therefore, since that time, the Department of Education has provided additional training opportunities to teachers serving students with disabilities, such as autism spectrum disorders, through Training and Technical Assistance Centers that are located in the eight superintendents' regions around the Commonwealth; and

WHEREAS, in recent years, some additional training opportunities for teachers of children with ASDs have become available, such as the Department of Education's Autism Priority Project Teams, George Mason University's online training program, and various courses offered by Virginia Commonwealth University, Regent University, and James Madison University as well as other Virginia institutions of higher education; and

WHEREAS, the Behavioral Health Care Subcommittee of the Joint Commission on Health Care has received presentations from school division representatives relating to the challenges of serving children with ASDs and did unanimously approve on November 10, 2005, the introduction of this resolution and the continuation of the study of autism in its 2006 workplan; now, therefore, be it

RESOLVED by the Senate, the House of Delegates concurring, That the Board and Department of Education and the Board and Department of Mental Health, Mental Retardation and Substance Abuse Services and other relevant entities be encouraged to take certain actions to improve the education and treatment of individuals with autism spectrum disorders. During the regulatory review and public comment periods for the proposed revisions to the Regulations Governing the Review and Approval of Education Programs in Virginia and the Virginia Licensure Regulations for School Personnel, the Board and Department of Education are urged to continue to implement initiatives designed to strengthen teacher qualifications, to include preservice and inservice professional development opportunities relating to the effective treatment of autism spectrum disorders, and to consider the treatment of autism spectrum disorders. Further, the Board and Department of Education are urged to examine appropriate educational placements considering the individualized educational plans of autistic students, the effects of mainstreaming, and the feasibility of alternative placements in public and private schools having qualified staff and adequate facilities. Finally, the Board and Department of Mental Health, Mental Retardation and Substance Abuse Services and other relevant entities are urged to continue to expand training opportunities that include approaches specifically addressing the needs of children with autism spectrum disorders; and, be it

RESOLVED FURTHER, That the Clerk of the Senate transmit a copy of this resolution to the

President of the Board of Education and the Commissioner of the Department of Mental Health, Mental Retardation and Substance Abuse Services, requesting that they further disseminate copies of this resolution to their respective constituents so that they may be apprised of the sense of the General Assembly of Virginia in this matter.

Appendix C

2007 SESSION

ENROLLED

HOUSE RESOLUTION NO. 60

Commending the Joint Commission on Health Care on its study of autism and its efforts to recommend a state agency to be designated as the lead agency on autism services for the Commonwealth.

Agreed to by the House of Delegates, February 20, 2007

WHEREAS, autism spectrum disorders are a cluster of developmental disabilities, significantly affecting verbal and nonverbal communication, social interaction, and activities of daily living that persist lifelong; and

WHEREAS, autism spectrum disorders represent a wide variety of intellectual and cognitive abilities that are complex in nature, and there currently exists no locus of planning and service delivery for this population in the Commonwealth; and

WHEREAS, persons with autism spectrum disorders frequently require intensive services and support from trained professionals in all aspects of learning, working, and daily life in order to become independent and productive members of society; and

WHEREAS, fifty percent of direct service providers felt unqualified to serve persons with autism spectrum disorders in a survey conducted under House Joint Resolution No. 228 in 2000; and

WHEREAS, the prevalence of autism spectrum disorders has increased significantly from four to five in 10,000 births in 1980 to a current prevalence of one in 166 births according to the National Centers for Disease Control, and the Commonwealth has recorded an equivalent increase in persons diagnosed with autism spectrum disorders; and

WHEREAS, services for this population in the Commonwealth are highly fragmented, and people with autism spectrum disorders do not have an agency that provides leadership in the areas of policy, planning, and service coordination in order to identify current and future needs and ensure that those needs can be met throughout the lifespan; and

WHEREAS, in its 2007 work plan, the Joint Commission on Health Care has agreed to study and recommend a primary agency for developing, coordinating, and overseeing autism services; now, therefore, be it

RESOLVED by the House of Delegates, That the Joint Commission on Health Care hereby be commended for its study of autism and its efforts to recommend a state agency to be designated as the lead agency on autism services for the Commonwealth; and, be it

RESOLVED FURTHER, That the Clerk of the House of Delegates prepare a copy of this resolution for presentation to the Joint Commission on Health Care as recognition of the agency's work on the issue of autism services and the importance of addressing the needs of persons with autism spectrum disorders.

ENROLLED

HR60ER

COMMONWEALTH OF VIRGINIA
HOUSE OF DELEGATES
RICHMOND

MICHÈLE B. MCQUIGG
POST OFFICE BOX 8
OCCOQUAN, VIRGINIA 22125

FIFTY-FIRST DISTRICT

COMMITTEE ASSIGNMENTS:
GENERAL LAWS (VICE CHAIRMAN)
COURTS OF JUSTICE
COUNTIES, CITIES AND TOWNS
SCIENCE AND TECHNOLOGY

January 9, 2007

Ms. Kim Snead
Executive Director
Joint Commission on Health Care
P.O. Box 1322
Richmond, VA 23218

Dear Ms. Snead:

On behalf of the Virginia Disability Commission, I am writing to commend the work of the Joint Commission on Health Care (JCHC) to address issues regarding Autism Spectrum Disorders (ASDs) in the Commonwealth. After hearing your presentation and other presentations on autism at its most recent meeting on November 13, 2006, the Disability Commission moved to endorse the 2007 work plan of the JCHC Behavioral Health Care Subcommittee on ASDs.

The stated objectives of the Behavioral Health Care Subcommittee with respect to ASDs, including enhanced services, training, and technical assistance for professionals and family members, and the recommendation of a primary agency for autism services in the Commonwealth, directly correspond to the goals of the 2006 Disability Commission. As such, the Disability Commission strongly endorses your approach and is willing to provide any possible assistance in this matter.

The Disability Commission has long maintained an interest in finding a statewide public agency "home" for autism and supports increased autism training and funding, especially in light of the growing autism population. We look forward to seeing your progress and hope that the Commission's endorsement will underscore the importance of your work.

Again, on behalf of the Disability Commission, thank you for your timely focus on this issue. We applaud your efforts and you have the Commission's full support.

Sincerely,

Michele B McQuigg

Delegate Michèle B. McQuigg,
Chairman, Virginia Disability Commission

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