

Behavioral Health Care Subcommittee

Joint Commission on Health Care

Autism Work Group Activities and Recommendations

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Executive Director
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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 and skills 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 education 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:

- 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.



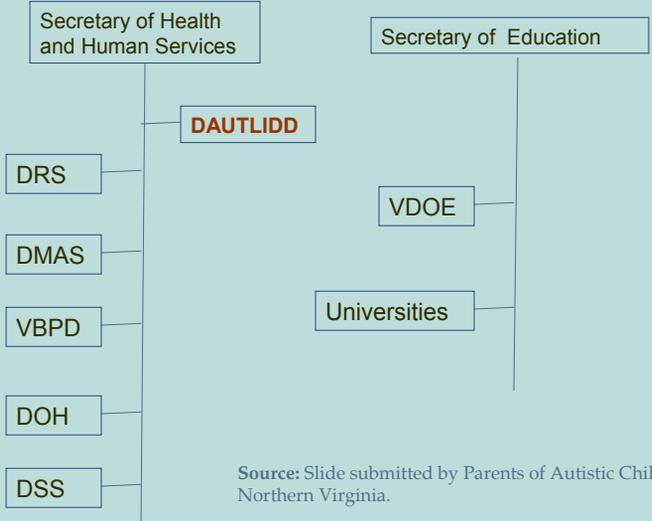
Department of AUTism and Lower Incidence Developmental Disabilities (DAUTLIDD) Option (continued)

- Individuals with dual diagnosis (Autism and MR) will be served by DAUTLIDD 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



Source: Slide submitted by Parents of Autistic Children – Northern Virginia. 23

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 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).



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.



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