

OFFICE OF THE SECRETARY FOR HEALTH AND HUMAN RESOURCES  
**REPORT ON “HOME” FOR AUTISM SPECTRUM  
DISORDERS AND DEVELOPMENTAL DISABILITIES**

In 2007, the Joint Commission on Health Care convened a stakeholder advisory committee to develop a recommendation to name an agency “home” for Autism Spectrum Disorders (ASD). The Commonwealth of Virginia has traditionally designated a state agency primary responsibility for the delivery and oversight of community and/or facility-based services for different disability populations. A specific agency has never been established for developmental disabilities as a whole, including people with ASD. Today, various state agencies are assigned responsibility for overseeing certain aspects of serving people with developmental disabilities (e.g. Education, Medicaid) and there is no single coordinating entity that monitors and develops policy for Virginia’s entire developmental disability system, including the system that serves people with ASD. With rising prevalence rates in Autism and ASD, the need to identify an agency in Virginia with primary responsibility and oversight of service delivery for individuals with ASD and for all people with developmental disabilities has become more urgent.

Background

The Joint Commission on Health Care convened a stakeholder advisory committee and prepared a variety of recommendations related to the potential agency “home” for ASD in 2007. While the advisory committee easily agreed that the recommendations should be expanded to include all developmental disabilities, it reached a stalemate to arrive at a single recommendation. The recommendations made included such a variety of options that the Joint Commission on Health Care requested that the Secretary of Health and Human Resources convene a second advisory panel to, not only arrive at a single recommendation for a state agency “home” for ASD, but to develop an implementation plan and time line for the agency to assume responsibility for the delivery and oversight of services to people with ASD.

The Secretary of Health and Human Resources (SHHR) convened a second advisory committee in August 2008, inviting those organizations and representatives that participated in the 2007 committee. The SHHR also included self-advocates that represented different types of developmental disabilities (Autism, intellectual disabilities, cerebral palsy, etc.) and their families (Attachment A).

The Secretary requested that the reconstituted group focus on developing a basic implementation plan for placing the “home” for ASD services at the Department of Mental Health, Mental Retardation, and Substance Abuse Services (DMHMRSAS). She requested that the stakeholder advisory panel pinpoint a plan for establishing a home for ASD, and recommend ways to move towards an umbrella system that would make DMHMRSAS the home for coordination and oversight of services for all developmental

disabilities. This would be in keeping with the recommendation made by the first JCHC committee in 2007.

The Secretary and DMHMRSAS contracted with a professional facilitator to lead the advisory group through its decision making process. The committee met on two different occasions to accomplish its task. The meeting on August 6 was organized to allow the group to begin identifying overarching issues and common themes to be addressed in its transition recommendations. The meeting on August 27 was an all day work session organized to identify the main steps to accomplish the transition and develop the associated time lines for transition.

### The System Envisioned for Developmental Disabilities

The stakeholder advisory committee was first asked to determine the long term picture of a system for all developmental disability services. In a facilitated brainstorming session, the committee members identified various themes for future developmental disability services across the Commonwealth. The stakeholders expressed a common desire for there to be increased access to services and supports, for there to be a choice in case management and service providers, for a uniform application of eligibility criteria to occur between system points of entry, for improved communication about available services through a variety of sources, and that above all the needs of individuals and families remain the primary focus.

With these fundamentals as the foundation, the stakeholder committee began identifying the challenges to in making DMHMRSAS the single state agency for developmental disabilities. The list of challenges was extensive, but easily fell into four categories/themes:

#### **1) Agency infrastructure:**

- How the current DMHMRSAS can be changed to include a practice area for ASD and developmental disabilities;
- Who would operate this practice area;
- Where would the practice area sit within the organization; and
- How would the practice area coordinate and interface with the Department of Education and other agencies and organizations serving people with developmental disabilities.

#### **2) Medicaid Services:**

- How would the current waivers serving people with developmental disabilities (i.e. DD Waiver, MR Waiver, Day Support Waiver) be modified to serve people with ASD who currently do not have access to services;
- How do we maintain or improve services for existing waiver recipients while serving a broader population; and
- Who should administer waivers and serve consumers at the local level.

### **3) Policy and regulation:**

- How can we ensure people ASD and other developmental disabilities are represented in the state's policy decision making processes;
- What operational principles and services have been successful under each waiver and should be applied across all waivers; and
- How can policies and regulations support a DD system that serves people with developmental disabilities and their families across the lifespan.

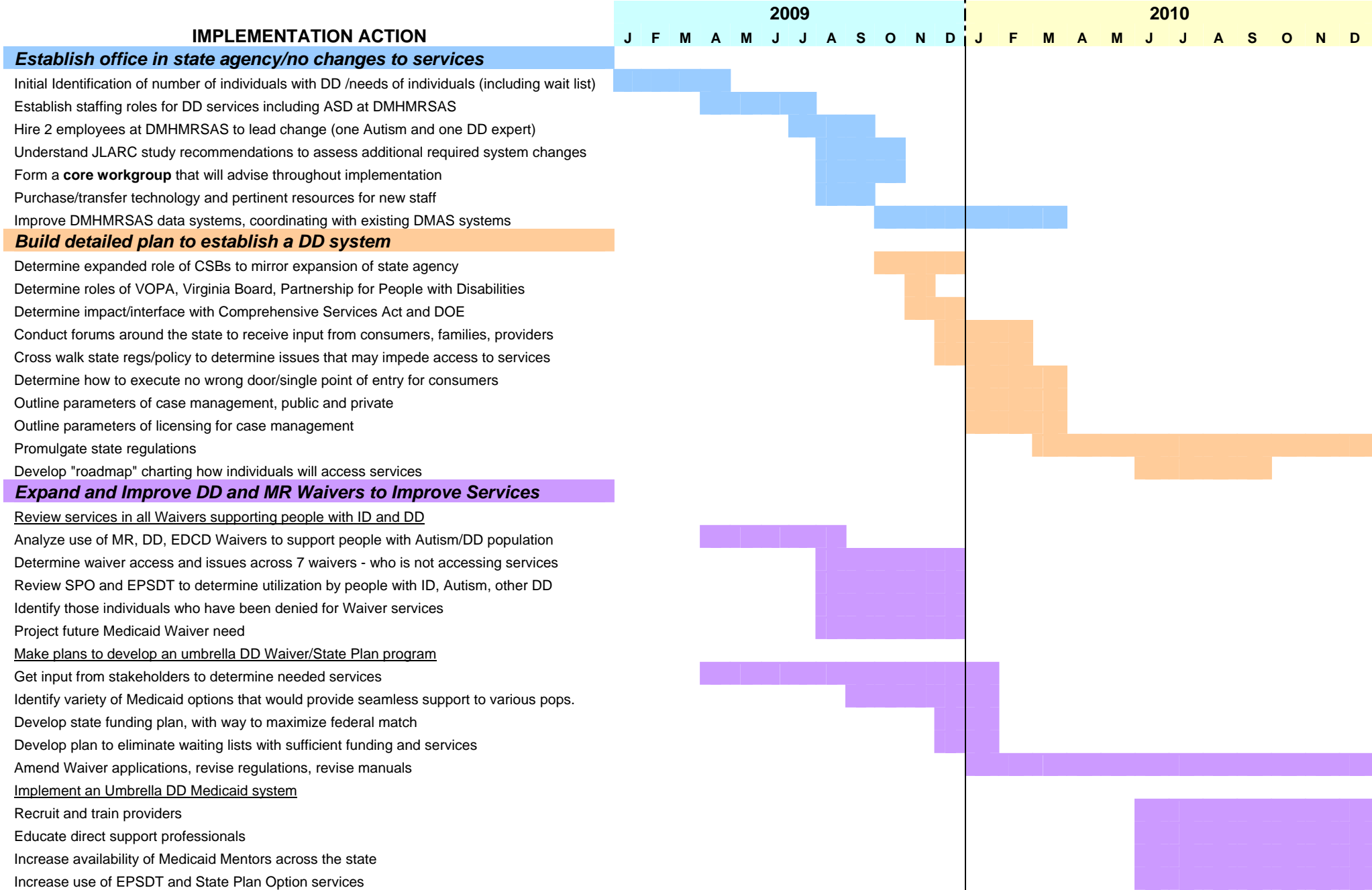
### **4) Services:**

- Is there payment equity across providers who provide similar services;
- Are there adequate services in all areas of the state; and
- How can conflicts of interest be reduced for consumers and their families who are selecting waiver service providers.

Using these themes, the work group began delineating specific action steps in each area to be accomplished in order for a successful agency transition to occur. These action steps and corresponding time lines are described generally below and contained in the following chart. It is important to note that this action plan does not incorporate assumed "sub-tasks" that would require completion for full and successful implementation.

**COMPLETION TIME LINE**

**IMPLEMENTATION ACTION**



## 1. Establish an Office at DMHMRSAS

The stakeholder group identified a practice area at DMHMRSAS as a critical step in moving toward a more comprehensive DD system. This DMHMRSAS office would include at least two people, hired from a pool of qualified persons who are currently not employed within the Department, who have expertise in ASD and developmental disabilities. These two individuals would be the key leaders in carrying out the rest of the implementation plan in concert with a core workgroup.

The core workgroup would be designated by the Secretary and would include:

- A person with an autism spectrum disorder
- A person with a development disability
- A person with an intellectual disability
- A family member of a person with a developmental disability
- Private providers
- DMHMRSAS
- Department of Medical Assistance Services (DMAS)
- Department of Education
- Office of Comprehensive Services
- Virginia Board for People with Disabilities
- VOPA

The workgroup would work with the new DMHMRSAS Office of DD Services to begin examining the JLARC autism study recommendations (due summer 2009) and begin implementing the items identified in the plan. In addition, it would examine current data systems existing at both DMHMRSAS and DMAS and determine ways to improve overall efficiency and operation of services through more integrated and coordinated systems.

## 2. Build a Detailed Plan to Establish a DD System

Phase 2 was a critical area of work and discussion for the stakeholder committee. Of paramount importance is the inclusion of people with disabilities and their family members at the table during every step of policy development, in this and all other phases. This includes individuals current using waiver services and those waiting for services.

This phase would focus on identifying pathways for people to access services. The stakeholder group would prefer a “no wrong door” pathway. This pathway will allow a person with a developmental disability to receive information, screening for services, and guidance at any place they touch the services system. So no matter what local or state government organization they contact, they can receive direction on how to apply for eligibility and information about services. In addition, the group

asked that the new Office and core workgroup examine ways to ensure that a “single point of entry” exists for services. This concept will ensure that regardless of disability, a person can receive services from a private provider or CSB if they choose and will not be turned away because of their disability.

This phase would also focus on determining how the DMHMRSAS Office of DD would coordinate policies and services with other government entities supporting people with ASD and other developmental disabilities, such as the Department of Education. It would examine what regulations would have to be changed or promulgated to ensure coordination and integration.

Lastly, the group recommended this phase focus on services and case management for individuals to ensure we have an adequate case management system in place to assist people and that case management is done by entities distinct from other service providers to minimize any conflicts of interest. Most importantly, the group requested an examination of ways to build service provider networks that are adequate to serve citizens with developmental disabilities across the entire state.

### **3. Expand and Improve DD and MR Waivers to Improve Services**

Phase 3 is the longest phase and would require extensive coordination between waiver recipients, DMAS, DMHMRSAS, private providers, and CSBs. This phase would specifically address the DD, MR, Day Support, and EDCD waivers. First, it would examine how we currently serve people with ASD and developmental disabilities. Second, through consultation with stakeholders, it would examine how we can improve services for the existing waiver recipients and reach citizens who currently do not qualify for services.

This work will require several steps, including exploration of the waivers, state regulations, federal regulations, and federal approval of any changes to the waivers. In addition, full implementation of this phase may require additional state funding to expand services under the waivers. The focus of this phase would be on the modernization of some of the waivers to move away from serving a specific disability population and toward providing the services necessary to support an array of developmental disabilities.

#### **Summary**

The merger of services to all individuals with developmental disabilities, including ASD, under one state agency umbrella will facilitate a more coordinated and integrated delivery system in Virginia. The recommendation to house ASD and developmental disabilities with DMHMRSAS and the corresponding action plan represents the best thinking of those stakeholders who partnered in this process to outline the steps necessary to envision the future and act on it.

ATTACHMENT A:

<b>Members in Attendance at August 6 and/or August 27 Meetings</b>	
<b>Name</b>	<b>Organization</b>
Ania Young	Faison School
Bradford Hulcher	Autism Society of Central Virginia
Carol Schall	Virginia Autism Resource Center
Carolyn Turner	VA Department of Rehabilitative Services
Christina Kuders	ASANV Self-Advocate
David Broder	Virginia Association of Personal Care Attendants
Fred Orelove	Partnership for People with Disabilities
Heidi Lawyer	Virginia Board for People with Disabilities
Helen Leonard	VA Department of Medical Assistance Services
Jamie Trosclair	The Arc of Virginia
Jennifer Fidura	Virginia Network of Private Providers
Jill Egle	The Arc of Northern Virginia
Joanne Boise	Virginia Department of Health
John Toscano	Commonwealth Autism Service
Joshua Wilson	DD Waiver Self-Advocate
Julie Stanley	Community Integration Advisory Commission
Karin Addison	American Academy of Pediatrics--Virginia Chapter
Kat Olsen	People First
Kim Lett	Virginia Association of Centers for Independent Living
Lee Price	DMHMRSAS
Linda Moore	A Voice for GAP Kids
Marie Ireland	VA Department of Education
Martha Toomey	Mary's Family
Mary Cole	Virginia Association of Community Services Boards
Sandy Hermann	Care Connection, CHKD
Tim Moore	A Voice for GAP Kids
Tracey Nordin	Alliance for Cross Disability Empowerment (ACE)