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.
**IMPLEMENTATION ACTION**

**Establish office in state agency/no changes to services**
- Initial Identification of number of individuals with DD /needs of individuals (including wait list)
- Establish staffing roles for DD services including ASD at DMHMRSAS
- Hire 2 employees at DMHMRSAS to lead change (one Autism and one DD expert)
- Understand JLARC study recommendations to assess additional required system changes
- Form a **core workgroup** that will advise throughout implementation
- Purchase/transfer technology and pertinent resources for new staff
- Improve DMHMRSAS data systems, coordinating with existing DMAS systems

**Build detailed plan to establish a DD system**
- Determine expanded role of CSBs to mirror expansion of state agency
- Determine roles of VOPA, Virginia Board, Partnership for People with Disabilities
- Determine impact/interface with Comprehensive Services Act and DOE
- Conduct forums around the state to receive input from consumers, families, providers
- Cross walk state regs/policy to determine issues that may impede access to services
- Determine how to execute no wrong door/single point of entry for consumers
- Outline parameters of case management, public and private
- Outline parameters of licensing for case management
- Promulgate state regulations
- Develop "roadmap" charting how individuals will access services

**Expand and Improve DD and MR Waivers to Improve Services**
- Review services in all Waivers supporting people with ID and DD
- Analyze use of MR, DD, EDCD Waivers to support people with Autism/DD population
- Determine waiver access and issues across 7 waivers - who is not accessing services
- Review SPO and EPSDT to determine utilization by people with ID, Autism, other DD
- Identify those individuals who have been denied for Waiver services
- Project future Medicaid Waiver need
- Make plans to develop an umbrella DD Waiver/State Plan program
- Get input from stakeholders to determine needed services
- Identify variety of Medicaid options that would provide seamless support to various pops.
- Develop state funding plan, with way to maximize federal match
- Develop plan to eliminate waiting lists with sufficient funding and services
- Amend Waiver applications, revise regulations, revise manuals
- **Implement an Umbrella DD Medicaid system**
- Recruit and train providers
- Educate direct support professionals
- Increase availability of Medicaid Mentors across the state
- Increase use of EPSDT and State Plan Option services
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 ECD 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:**

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