

ONE COMMUNITY

**INTERIM REPORT OF THE TASK FORCE
TO DEVELOP AN OLMSTEAD PLAN
FOR VIRGINIA**

Adopted for Public Comment
March 26, 2003

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PART I--INTRODUCTION

A. WHAT IS THE “OLMSTEAD” DECISION?

In 1999, the United States Supreme Court issued a decision in the case of Olmstead v. L.C., 119 S. Ct. 2176 (1999). This case involved a challenge under Title II of the Americans With Disabilities Act (ADA), 42 U.S.C. § 12132, by two women with mental disabilities who lived in mental health facilities operated by the state of Georgia, but who wished to live in the community. The U.S. Supreme Court held that Georgia had violated the ADA by forcing these women to remain in a state mental hospital after their treating professionals had determined them to be ready for discharge.

In the decision, the Court held that a State is required under Title II of the ADA to provide community-based treatment for persons with mental disabilities when:

- The State’s treatment professionals determine that such placement is appropriate;
- The affected persons do not oppose such placement; and
- The placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with disabilities.

Although the Olmstead case involved two individuals with a mental disability, the decision applies to all persons with disabilities who are covered under the ADA.

B. WHAT IS THE OLMSTEAD TASK FORCE?

In Item 329 M of the 2002 Appropriation Act, the General Assembly directed that:

The Commissioner of the Department of Mental Health, Mental Retardation, and Substance Abuse Services shall convene a task force to develop a plan for serving persons with disabilities that implements the recommendations of the Olmstead decision (Olmstead v. L.C., 119 S. Ct. 2176 [1999]). The members of the task force shall represent the interests of consumers who may be impacted by the plan as well as a broad array of service providers at the state and local level. The task force shall report regularly to the Joint Commission on Health Care and accept input from the Commission as the plan is developed. All agencies of the Commonwealth shall provide assistance to the task force in its development of the plan, upon request. The task force shall submit its final recommendations to the Governor, the Chairmen of the House Appropriations and Senate Finance Committees, and the Chairman of the Joint Commission on Health Care by August 31, 2003.

The task force was convened July 31, 2002 and has met five times: July 31, 2002, September 26, 2002, November 4, 2002, January 7, 2003, and March 26, 2003. *At its March 26, 200, meeting, the Task Force adopted this Interim Report to be distributed for public comment.*

Two additional Task Force meetings are planned. On June 9, 2003, the Task Force will meet for a public comment period and will consider recommendations for implementation strategies, priorities and time frames. On July 28, 2003, the final Task Force report will be adopted. A copy of the Task Force's Workplan is attached at Appendix A.

C. WHO IS ON THE TASK FORCE?

The task force is chaired by The Honorable Jane H. Woods, Secretary of Health and Human Resources, and has more than 60 members representing consumers, family members, advocates, providers, local government and other stakeholders.

Fourteen (14) state agencies that provide services to individuals with disabilities are assisting DMHMRSAS by serving as members of the Task Force and providing resources to support the task force.

A list of the task force members appears in Appendix B.

D. HOW IS THE TASK FORCE DOING ITS WORK?

The Task Force is completing its work using two concurrent planning processes:

1. **Gathering information and data on disability populations and services.** The state agencies are responsible for assembling this part of the Plan that will describe:
 - The disability population groups;
 - Current services and service capacities for each group;
 - Prior accomplishments in addressing the expectations of the Olmstead decision;
 - Current practices and processes for accessing institutional services; and
 - Services choices and existing service gaps by major service categories.

To assist, the agencies developed a Facilities and Residential Program survey.

Additionally, a Consumer and Family Feedback Form was developed so that individuals with disabilities and their family members are extended an opportunity to tell the Task Force about themselves and their opinions. This form is available from any Task Force member and at www.olmsteadva.com until the end of May 2003.

Populations and services information will be included in the Task Force's final report in August.

2. **Exploring barriers to community services and supports through “Issues Teams.”**

At its first meeting, Task Force members identified major issues that cut across populations of individuals with disabilities, and they formed seven Issues Teams that have been meeting to examine those issues. State agencies served as conveners of these Teams. Each has a chairperson, who is not a state agency employee, and a recorder. Each Team is comprised of both Task Force members and interested individuals who are not Task Force members. Those teams are:

- Accountability
- Educating the Public, Consumers and Families
- Employment
- Housing
- Prevention and Transition Services
- Qualified Providers
- Transportation
- Waivers

Task force members served as members of the teams, and all teams invited interested non-task force members to serve as members of their teams. A summary of the chairpersons, recorders, agency conveners, members and meeting dates of each Team is attached at Appendix C.

The Chairs of the Issues Teams and several state agency representatives comprise the Steering Committee for the Task Force.

The work of the Issues Teams to date is the subject of this Interim Task Force Report.

PART II---REPORTS OF THE ISSUES TEAMS

In the course of their work, all Issues Teams repeatedly stressed the importance of broad participation and input from individuals with disabilities and their families. Each Team submitted a statement certifying that it was representative of, and considered, the interests of all disability populations in its work. Each Team also developed and adopted a vision and values statement to guide its work.

The Teams identified issues related to their topic and, for each issue, included as applicable the following information in their reports:

- Description of the issue;
- Background and data;
- Relationship between the issue and current laws, regulations and policies;
- A brief description of current programs and initiatives addressing the issue;
- Identification of the disability populations impacted by the issue and how they are impacted;

- Challenges;
- Options (with a discussion of the advantages and disadvantages of each); and
- Recommendations and rationale for selecting the recommendations.

Some Teams included any other related information as well. The Team Reports, in their entirety, are set forth below.

In the preparation of this Interim Report, task force members identified two fundamental concepts:

1. Some individuals with disabilities lack the capacity to make some or all decisions and choices for themselves. Every such individual should have a means by which decisions and choices may be made on his or her behalf. Among many other examples, some individuals may have an advance directive, and others may need a substitute decision-maker appointed and available to act on their behalf. The substitute decision-maker could be a family member chosen in the order set forth in the Health Care Decisions Act, § 54.1-2986 of the Code of Virginia, a guardian, or other legally authorized representative. Unless the context indicates otherwise, wherever reference is made to a decision or choice by an individual with a disability in the reports that follow, the decision or choice may be made by an appropriate substitute decision-maker for individuals who cannot make the decision or choice independently.
2. The Task Force recognizes, and is developing an Olmstead Plan that reflects, the importance of Virginia's full continuum of care, from self-care through institutional care.

A. REPORT OF THE ACCOUNTABILITY TEAM

Team Chair: E. W. Cline, Jr.

Team Recorder: Kate Gaston

Agency Convener: Jonathan Martinis, Virginia Office for Protection and Advocacy (VOPA)

Membership of the Accountability Team included a number of consumers and family members; the team was also well represented through both membership and participation of advocacy groups, state level departments and organizations, and local government representatives.

Vision and values: An accountable system must be based on:

- Fairness and equity for all persons covered by the Olmstead decision;
- Meaningful choices driven by the needs and preferences of consumers, families, and guardians;
- A clear connection between system goals and actual system outcomes;

- Government programs and supports that reflect a philosophical and budgetary commitment to the requirements as set forth in the Olmstead decision; and
- A system that has clear criteria for current and new funds to insure that such funds are spent/distributed in a manner that is supportive of the rights of families, consumers, and guardians to select from appropriate options and choices within available resources.

All disability populations are impacted by the following issue.

ISSUE: FRAGMENTED DATA SYSTEMS UNCONNECTED TO OLMSTEAD

DESCRIPTION OF THE ISSUE: *Current data gathering and evaluation systems are fragmented and unconnected to Olmstead compliance and implementation. Without adequate information structures, maintaining focus on overall progress towards maximum consumer and family choice will be difficult.*

Early on, the Team identified the following interrelated issues:

- Where will the responsibility rest for ongoing, comprehensive oversight of all the systems involved in implementing changes required by Olmstead?
- What will be the continuing mechanisms for capturing voices of consumers?
- What is the best way to assess the effectiveness of programs targeted at educating families, consumers, guardians and providers regarding requirements for meaningful choice?
- What type of management system is needed to provide quick resolution of problems impeding the timely implementation Olmstead requirements?
- Choices for families, guardians and consumers must clearly acknowledge that options must be available in a range of appropriate settings, including facility-based and community-based services and supports. The goal should be to focus on maintaining the maximum amount of options possible and should not seek to impose a “one-size-fits-all” solution for consumers and families.

Background and data: No comprehensive system exists to provide organized information that would:

- Assess overall Olmstead and ADA compliance. Real choice, by necessity, involves a wide range of systems including, in part, basics required for survival (for example, basic living supports and appropriate housing), basic and specialized medical services, access to social supports, and appropriate employment options.
- Measure the Commonwealth's progress over time in implementing its Olmstead Plan. The absence of appropriate benchmarks and assessment over time will provide insufficient information to assess long-term effectiveness of the plan. The current fragmentation of information gathering and data collection systems necessary to appropriately assess progress will continue to be a major problem unless it is directly addressed and resolved.

- Aid in developing future changes to the plan that are based on past performance and current needs. Too often good plans are developed and sit on a shelf, or bad plans continue which actually do harm when outcomes are inadequately evaluated, and corrective actions are not a natural part of the assessment process. A successful assessment process must include a mechanism to alter plans and redirect funding and programs to better accomplish agreed-upon changes.

Relationship between the issue and current laws, regulations and policies: In most instances, Accountability Team recommendations will need to be developed in response to the recommendations of the other Teams. Assessment of the other individual Team recommendations is required to determine their potential impact on state and federal laws, regulations, and policies. The impact of local laws and ordinances, policies, and regulations may also need to be assessed.

Responsibility for legal and regulatory compliance with the Americans with Disabilities Act (ADA) is scattered among a number of organizations involved in operating, paying for, and regulating supports, services, and care for individuals who fall under the ADA umbrella. At its broadest, an assessment of ADA compliance would need to include licensing and oversight organizations such as:

- Those operated to regulate basic health services (for example, nursing homes, hospitals, and related medical facilities); the Department of Social Services (for example, assisted living facilities (ALFs) and programs licensed to serve children); and those licensed by the Department of Mental Health, Mental Retardation and Substance Abuse Services.
- General rights protection and advocacy programs and departments (for example, the Virginia Office for Protection and Advocacy (VOPA); the Office of the Inspector General which is responsible for oversight of mental health, mental retardation and substance abuse services in both facilities and community-based systems of care; and the State and Local Human Rights Committees.)
- Payers and funders of services and supports (for example, organizations managed under the Office of the Secretary of Health and Human Resources).
- Additionally, systems outside of the Office of the Secretary of Health and Human Resources must be considered in assessing the Commonwealth's efforts at complying with the requirements set forth in Olmstead. Of particular importance are areas that affect the availability of basic living supports and community integration options (for example, basic essentials for living, stable housing, basic and specialized medical care, and access to long-term employment options), and the risk that covered individuals have of falling into inappropriate systems due to inadequacy of support systems (for example, those persons covered under the ADA who may enter the correctional system due to lack of alternative supports).
- State level departments responsible for developing operating policies for both state and local programs as well as privately operated service delivery and support systems. Currently, there is no single source of data to draw upon in order to assess overall ADA compliance in general and Olmstead compliance in particular.

Challenges:

1. Service infrastructure and design: The current infrastructure provides very limited comprehensive or uniform reporting or data gathering regarding overall ADA compliance and, more specifically, Olmstead compliance. For adequate assessment of changes required for compliance, a uniform system is needed which clearly evaluates current compliance, maintains ongoing information for future planning, and has a clear process to take corrective action based on this information. From a governmental perspective, these systems must also provide a mechanism to demonstrate an effective state response to the mandates as set forth under ADA and clarified by the U.S. Supreme Court's Olmstead decision. Additionally, the hard data that this system must gather has to incorporate meaningful consumer, family, and guardian participation and input. This focus will be important not only in terms of protecting rights under ADA, but it will also be essential in order for the Plan to have long-term credibility among the people it is designed to protect and support.
2. Monitoring and oversight.
3. Data/information system issues.

Options:

- AOpI.1.a. The first option involves best use of existing compliance/regulatory resources and reporting systems. Coordinated activities should maximize use of current state reporting resources and provide for a more comprehensive review of progress in responding to Olmstead.

The major advantage of this option is the potential for reducing the overhead associated with data collection and analysis. The major disadvantages and problems with implementation will be the natural tendency or resistance of organizations from disparate parts of government to coordinate data collection activities. Coordination of these activities is essential to maximizing the effectiveness of current resources in assuring compliance with appropriate quality standards, and at the same time minimizing the expenditure of resources for unnecessary or duplicative oversight.

- AOpI.1.b. The second option proposes the development of an independent review of overall Olmstead compliance.

The main advantage of this option would be the independence of the evaluation process and the consolidation of existing data systems related Olmstead compliance evaluation. The obvious disadvantage would be that some added cost would be incurred to accomplish its task.

Combining the two options is recommended.

Recommendations and rationale for selecting the recommendations:

- AI.1. Develop a continuous information gathering and evaluation system that is totally separated from the service provision and funding systems.

The Accountability Team's suggestion is to develop a program affiliated with University and College systems that have appropriate assessment and research capacity and that would be willing to accept ongoing responsibility for using existing data and developing necessary independent data systems to properly assess general ADA compliance and, more specifically, compliance with the requirements as set forth in the Olmstead decision. Such a program must assume ongoing responsibility to ensure, to the extent possible, that information gathered by state agencies for selected disability groups is meaningful. For example, is the information cited current? Is the information cited readily available? How is the information generated? How often is the information collected? Through a review of state agency documentation for specific disability groups, the Accountability Team may be able to identify data elements that could be used for ongoing monitoring of the Olmstead plan post-implementation. This university/college based evaluation project should report back to the Olmstead Task Force (or its successor) to review the data gathered as part of this process. It is further recommended that the Task Force solicit public comments on any published reports and recommendations developed as part of this process. This review (and the related comments) would result in recommendations to the executive and legislative branches of government regarding proposed changes in the implementation plans developed as part of the Olmstead Task Force. Any data sets developed by this evaluation project must focus on overall Olmstead requirements and not be limited to assessing just one aspect of Olmstead compliance. A primary concern in developing any assessment or outcome measures is the requirement that these measures be focused on and responsive to consumer and family interests. Further, these data sets must be developed to support system changes in funding and a need for new funding in order to achieve full ADA compliance. Obviously some cost will be involved, and the Accountability Team will need to consider possible funding options for this project as part of its final recommendations.

- AI.2. The Executive Branch should review existing organizations and requirements relating to oversight and compliance issues in order to remove inconsistencies and lessen redundant data collection burden related to areas such as:

- Licensing
- Department of Medical Assistance Services (DMAS)
- Human rights
- Accreditation groups

Given severe limitations for possible new funding, it is vitally important that the Executive Branch pursue efficiencies by eliminating overlaps and redundancies in current accountability systems. A concerted effort should be undertaken to assess the true costs

of individual and organizational record-keeping systems (for example, billing systems, individual case records, and eligibility processes).

AI.3. Make consumer feedback an integral part of the data collection systems developed and used by providers, governmental decision makers, and oversight organizations. These systems must:

- Be directly linked to consumers, families, and guardians;
- Reflect consumer involvement in planning (on both an individual and system basis);
- Assess actual changes in consumers' lives, with a particular focus on measuring adherence to choices selected by consumers, families and guardians;
- Have some independent process to evaluate the actual degree of influence that consumers, families, and guardians have on systems of services, and supports; and
- Measure choice in terms of flexibility of funding and availability of services and supports, with particular emphasis on geographic availability and adequacy of funding to provide needed services and supports.

AI.4. Develop specific accountability measures based on recommendations and solutions proposed by other Teams.

Specific timelines will need to be developed and must integrate all of the recommendations from the individual Teams. This integration will be critical in assessing the success of the Task Force's plans as well as overall Olmstead compliance.

AI.5. Review the reports of the eight issues teams with particular attention to challenges related to monitoring and oversight and data/information system issues.

Identifying gaps in data systems is essential to the development of an effective evaluation and monitoring system. After reviewing state agency summaries of information relating to specific disability groups (11 such groups were identified in the original charge to the Task Force), future surveys and monitoring systems should be structured so that the results fill existing information gaps.

AI.6. Develop a concept document that begins with an explanation of the philosophy underlying the recommended approach to the assessment of the implementation and effectiveness of the Olmstead plan. Within the concept document, identify key variables of interest and the methods for collecting information about them. Clearly articulate the need for multi-method research to fully and comprehensively assess the implementation and effectiveness of the Olmstead plan. Relate different research methods to the assessment of different aspects of the Olmstead plan. (For example,

secondary data analyses would be a cost-effective way to look at certain issues related to the cost of institutionalization. Web-based or mail surveys may be a meaningful way to gather information from service providers. Field interviews with disability-specific questions may be necessary to gather meaningful information from “hard-to-reach” populations). This is where review of state agency reports and issue teams reports will be particularly helpful. These reports will contain information about readily available data and data gaps.

Within the concept document:

- Clearly articulate the need for human and financial resources to fully and comprehensively assess the implementation and effectiveness of the Olmstead plan. To the extent possible, estimate the cost associated with the recommended assessment activities;
- Provide an estimated timeline for assessment activities in light of the timeline for the implementation of the Olmstead plan. This will provide the Olmstead Task Force with tangible evidence that the assessment is feasible and that results will be available to inform further program and policy initiatives within a reasonable time frame; and
- Include a diagram that illustrates the linkages between various aspects of the assessment. Since the assessment would be large in scope, it is important that Olmstead Task Force members see that what is recommended in the concept document is reasonable.

Involve the Survey and Evaluation Research Laboratory at VCU, or a research entity of the Accountability Team’s choosing, to help with the development of the concept document. It is likely that assessment activities will require outside research support. Including researchers in the development of the concept document is imperative.

B. REPORT OF THE EDUCATING THE PUBLIC, CONSUMERS AND FAMILIES TEAM

Team Chairs: Janet Bixby, Co-Chair
Ann Cutshall, Co-Chair

Team Recorder: Stacey Atwell

Agency Conveners: David Suttle, M.D., Virginia Department of Health (VDH)
Stacey Atwell, Department of Mental Health, Mental
Retardation and Substance Abuse Services

On the Educating the Public Consumers, and Families Team, there are three people with disabilities, two of whom are co-chairs. At least five parents of children with disabilities have served as members of the Team. There may be more in both groups, but some

members have had limited participation and some have not chosen to disclose their situation.

Vision and values:

The Educating the Public, Consumers, and Families Team views educating the public, consumers and families as the responsibility of all members of the Olmstead Task Force. Every activity the Task Force, Steering Committee and Issues Teams undertake should be approached and promoted as an educational opportunity. The Educating the Public, Consumers and Families Team challenges the entire Olmstead Task Force to utilize all available meetings, contacts, and opportunities to continuously educate consumers, family members, the public and each other to the Task Force's objective of improving self determination and independence of consumers.

We also believe that the dissemination of reliable information and the facilitation of clear communication are, now and after the end of this planning process, the responsibilities of this Team. We believe that appropriate education for consumers, providers, legislators, and the general public is the keystone of a successful Olmstead Plan, and our recommendations will ensure that such wide-ranging education will be a part of Virginia's final Olmstead Plan. Finally, we will research and develop communication and educational tools, materials and resources to disseminate to the Task Force for its use.

Relationship between the issues and current laws, regulations and policies:

State: Although the Community Services Performance Contract between the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) and the Community Services Boards has included a provision for education, this is a transient requirement, for it can be changed annually. There is no statutory provision that both the state agencies that support persons with disabilities and the community boards and committees for the various disabilities have education provisions. The law for all support programs for persons with disabilities should be amended to require an education component for the subject class, for providers for those individuals, and for the public, such that the Olmstead provisions are referenced and explained as they apply to the subject class of persons with disabilities.

State: The "maximum feasible involvement and participation of consumers and the families of consumers in policy formulation and services planning, delivery, and evaluation" is mandated in Va. Code § 37.197.14 for the Community Services Boards (CSBs); this provision seems to be honored in the breach. There is no similar provision for DMHMRSAS itself, nor for that matter for other services in the Commonwealth. This provision should be extended to other boards and departments subject to the Olmstead decision. An agent should be designated to report regularly to the Governor, the General Assembly, and the public as to the implementation of these provisions. In the mental health area, the Mental Health Planning Council (MHPC), in accord with its federal mandate, should be by Virginia statute included in such monitoring and reporting,

and made the primary venue for planning review, monitoring, and evaluation. The DMHMRSAS Inspector General (IG) should also be included in such a coordinated program of monitoring and evaluation, with the provision that consumers and the families of consumers be included in the IG's program of monitoring and evaluation, as is already the case with the MHPC.

State: The State MHMRSAS Board is limited in practice to ensuring "the development of programs to educate citizens and to elicit support for the activities of the Department and of community services boards" under Virginia Code § 37.1-10.7. As such, it has a limited public relations role for the institutions and the CSBs. The State MHMRSAS Board should be given power to ensure the inclusion of the Olmstead decision and this Olmstead plan in appropriate provisions and education, by its powers under Va. Code § 37.1-10 to (1) develop and establish programmatic and fiscal policies governing the operation of state hospitals and community services boards; and (2) ensure the development of long-range programs and plans for mental health, mental retardation and substance abuse services provided by the Commonwealth and by community services boards. The State MHMRSAS Board should report annually to the Governor, the General Assembly, and the public as to the implementation of these provisions.

Federal: All titles of the Americans with Disabilities Act (ADA)
Section 504 of the Rehabilitation Act of 1973

Current programs and initiatives addressing the issues:

1. The *National Council on Independent Living* produces much material on independent living that could be used by consumers and their families. Its satellite program, the Independent Living Resource Utilization, sponsors regular teleconferences on various subjects of importance and makes recordings of them available. They also publish regular readings on independent living that would be useful, especially to professionals.
2. The *Mid-Atlantic Americans with Disabilities (ADA) Center* publishes a regular newsletter and offers free trainings on various aspects of the ADA. This offers an opportunity for consumers and anyone interested to learn their rights.
3. As part of its work as advocate, the *Virginia Office for Protection and Advocacy* offers much information to consumers and their families, both by phone and through training sessions when invited to do so by providers or consumer groups.
4. Through its partners program to train people with disabilities and their families, the *Virginia Board for People with Disabilities* provides valuable education on the laws regarding disability and the methods for using them. The Consumer and Family Training Fund also provides the means for consumers and their families to become more educated about disabilities by attending relevant conferences.
5. *The Arc* distributes much information on cognitive disabilities to its members through newsletters and other publications. Local groups hold training for consumers and their families.
6. *Disability Service Boards (DSBs)* and the state board that governs them provide advocacy and funding to organizations serving people with physical and sensory

disabilities. Many of the projects they have funded have been, and could continue to be, educational.

7. *Virginia Assistive Technology Services (VATS)* is a state organization that has regularly provided conferences to educate both consumers and providers about the use of technology. VATS should be an excellent resource for providing the education in new tools for communicating which can bring together widely scattered and diverse consumers and providers.

In addition to those listed above, the Team has identified programs, initiatives, and services that may also currently exist, including (but not limited to):

- Parent Resource Centers (information and resources for parents of special education students)
- Mental Health Association (MHA)
- National Alliance for the Mentally Ill (NAMI)
- People First
- Parents and Associates of the Institutionalized Retarded (PAIR)
- Parents and Children Coping Together (PACCT)\
- Coalition for Mentally Disabled Citizens of VA
- VA Depressive and Manic Depressive Association
- Parent Educational Advocacy Training Center (PEATC)
- Action Alliance for Virginia's Children and Youth
- Department of Aging Center for Elder Rights
- Local Area Agencies/Councils on Aging
- Alzheimer's Association
- Virginia Autism Resource Center
- Voices for Children
- Department of Aging (DOA)
- Department of Education (DOE)
- Department of Social Services (DSS)
- Department of Rehabilitative Services (DRS)
- Partnerships for People with Disabilities
- Virginia Department for the Deaf and Hard of Hearing (VDDHH)
- Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS).

Many other programs/services likely exist; however, identifying these would require a survey to locate all relevant initiatives across Virginia.

ISSUE I: IDENTIFYING TARGET AUDIENCES

DESCRIPTION OF THE ISSUE: *Because of the diversity of populations that must be educated about the Olmstead Plan, both content and approach must be widely varied, and a major outreach effort is required. The various populations that must be reached are widely scattered and not always well defined.*

Disability populations impacted by the issue and how they are impacted: Consumers in all populations are impacted. Additionally, family members, providers, the public, and legislators are all directly or indirectly impacted by Olmstead and Olmstead-related initiatives. If all potentially impacted populations are not initially identified, individuals may be inadvertently left out of the planning and implementation processes.

Challenges:

1. Difficulty in locating target audience
2. Difficulty in addressing diversity of target audience
3. Difficulty in outreach
4. Differing definitions of populations and categories

Recommendations and rationale for selecting the recommendations:

EdI.1. Send a postcard to all consumers and family members who fill out a consumer feedback instrument when the draft of the Olmstead Plan is ready for public comment, advising them of its availability, giving them the website where it could be found, and offering a number to call if they prefer it in hard copy or alternative format.

This would be a first step in connecting with a large group of consumers in an ongoing way.

EdI.2. Establish plans for the creation and distribution of radio spots and public service announcements and the arrangement of interviews on local talk shows.

This seems like one of the best and least expensive ways to reach those consumers and family members who are outside the system.

EdI.3. When the Olmstead Plan is ready for public comment, distribute a press release through the Governor's Office Press List, and the Virginia Press Association.

This would seem to be the most efficient way to reach a large number of newspapers statewide, and would also be relatively inexpensive.

EdI.4. Prepare for and distribute a press release to newsletters of faith communities and community organizations telling them about the availability of the Olmstead Plan for comment.

This would be a very efficient and inexpensive way of reaching a large number of people. Newsletters are often eager for material, so the chances of being publicized in this way are very good.

ISSUE II: FEAR OF STIGMA OF DISABILITY

DESCRIPTION OF THE ISSUE: *It is difficult to share information with people when they fear the topic. Misunderstandings, “magical thinking” (i.e., if the disability is ignored, it will go away), and traditional negative attitudes may comprise an emotional barrier that often shuts people out from the discussions in which they need to participate. Self-esteem may also be affected.*

Disability populations impacted by the issue and how they are impacted: Stigma affects all populations and must be addressed as a systemic issue of concern.

Challenges:

1. Lack of education about disability
2. Lack of association with people with disabilities
3. Magical thinking (“What I don’t mention won’t exist”)
4. Traditional attitudes and cultural attitudes

Recommendations and rationale for selecting the recommendations:

EdII.1. Encourage disability awareness activities and activities that build relationships among people with disabilities and others.

Disability awareness activities can offer the public opportunities to learn about disabilities in a positive and often social or entertaining way that can dispel anxiety. Also, relationships formed with individuals with disabilities are the best way of getting rid of fears, stereotypes and prejudice.

EdII.2. Encourage strong, visible organizations of consumers and family members.

This public exposure can help the public to perceive people with disabilities as a competent, functioning part of our society.

EdII.3. Provide more opportunities for people to volunteer within the disability community, such as mentoring programs and provide similar opportunities for people with disabilities to volunteer in able-bodied groups.

Working with someone on a project or helping them in some way is one of the best ways of getting to know them.

ISSUE III: APATHY

DESCRIPTION OF THE ISSUE: *The first task of an educational program must be to draw the attention of the intended target audience. Due to the growing number of issues and programs that require on-going attention, it is difficult for all individuals to be aware of all disability-related programs. As a result, individuals often give of their time and attention only to those things that directly and personally impact them. Consequently, all educational programs fight against apathy.*

Disability populations impacted by the issue and how they are impacted: All populations focus on many different issues; not everyone understands Olmstead well enough to know how it will impact them.

Challenges:

1. Information not personally relevant
2. Too many competing distractions
3. Information overload
4. Protection from involvement

Recommendations and rationale for selecting the recommendations:

- EdIII.1. Create a program for the systematic accumulation and distribution of human-interest stories, either about people who have made successful transitions into the community, or about peoples' needs for the diversity of choices that a good Olmstead Plan would provide.

In order to make the Olmstead Plan relevant to the average person, it needs to be understood in terms of individual lives that touch hearts.

ISSUE IV: LACK OF COMMUNICATION METHODS AND TOOLS FOR ALL AUDIENCES

DESCRIPTION OF THE ISSUE: *Because of the mushrooming technology and newly developing techniques for disseminating information effectively, it is difficult for people outside the technology field to maintain sufficient knowledge to educate themselves as effectively as possible. Also, different disability groups communicate differently, and a variety of differing needs must be considered. Finally, lack of access to effective communication methods (for example, computer access) and limited education regarding*

the use of those methods are barriers to successful communication. (Responsible entities include: state and local governments, disability organizations and agencies and others.)

Disability populations impacted by the issue and how they are impacted: Consumers in all populations, family members and providers often have difficulty in accessing and utilizing new technology and communication methods for a variety of reasons (for example, cost, availability, and technical knowledge or skill).

Challenges:

1. How to develop new tools and methods
2. Need for multimedia presentation of information
3. Need for alternative formats
4. Lack of access to modern technology, for example, computer skills and equipment

Recommendations and rationale for selecting the recommendations:

EdIV.1. Make a draft of the Olmstead report available in alternative formats.

This is the law and, besides, many people will never read the Plan unless it is in Braille, on tape, or in other alternative formats.

EdIV.2. Make the draft of the Olmstead Plan available in Spanish at least, and, if possible, also in Korean.

We are an increasingly multilingual nation, and effective communication has to take account of that. It is the experience of this team that the largest populations requiring a foreign language with whom we have contact are Spanish and Korean.

EdIV.3. Virginia Assistive Technology Service (VATS) should sponsor a communications workshop for consumers and their families and providers on communicating with a culturally diverse population. Sessions should focus on a variety of technology and include ideas for working with the media.

Consumer and family organizations and small agencies need to be equipped to help get out the message about Olmstead. By helping them, we also insure that they will be able to reach and serve more people.

EdIV.4. Initiate a quarterly Olmstead newsletter to relate success stories, progress and ongoing progress.

Besides providing a constant connection with a large number of people and providing long-term education on the plan, this newsletter would be a resource to anyone seeking to publicize information about it.

ISSUE V: HUGE, DIVERSE DISABILITY POPULATION

DESCRIPTION OF THE ISSUE: *Educating the consumer is key to the success of any plan, but many consumers are still outside the “system.” Some are hiding their disabilities or they are hiding because they have a disability, while some depend on others for their information. All of these factors create challenges for Olmstead educational initiatives. (Responsible entities include: local and state governments and providers.)*

Disability populations impacted by the issue and how they are impacted: The disability populations are extremely diverse and represent the entire range of disabilities. All disability groups are represented in the Olmstead process and must understand the needs of each distinct disability population. Each disability population, including consumers and family members, must learn how Olmstead will impact not only their own disability population, but also all other disability populations.

Challenges:

1. Many outside normal systems and organizations
2. Widely scattered
3. Many hidden disabilities
4. Requirement for varied communication methods
5. Many depending on others for information
6. Many invisible disabilities

Recommendations and rationale for selecting the recommendations:

EdV.1. Encourage widespread posting of notices in public places offering help to people with disabilities who request it.

People with disabilities who know they can receive assistance are more likely to admit their disability and communicate about their needs.

EdV.2. Require service providers to have detailed procedures for notifying people with disabilities of available help.

If people were sure they could be accommodated, they would be less likely to fall through the cracks because of misunderstandings.

ISSUE VI: DIFFERENT VALUES REGARDING DISABILITY

DESCRIPTION OF THE ISSUE: *Differences in cultural and religious values systems may be barriers to effective education of people with disabilities. For example, if a person believes that an accommodation would show a lack of faith or prevent healing, any education designed to cope with a disability may be resisted. (Responsible entities include: religious organizations, providers and others.)*

Disability populations impacted by the issue and how they are impacted: All populations must consider and respect differing values throughout the planning process, including religious and cultural value differences.

Challenges:

1. Values shaped in childhood
2. Need to involve religious, ethical and cultural communities
3. Negative attitudes taught by some cultural groups

Recommendation and rationale for selecting the recommendation:

EdVI.1. Create a pamphlet for faith groups and cultural groups for the purpose of dealing with negative attitudes about disability and beliefs that foster poor adjustment.

Some negative attitudes and beliefs perpetuated by some cultural and faith groups make it difficult for people to adjust to disabilities. A pamphlet such as this would suggest ways of helping people to re-examine these values.

ISSUE VII: FUNDING

DESCRIPTION OF THE ISSUE: *Most educational efforts will require a level of funding. Governments, especially state government, do not make such funding a priority. This is especially important during the transitional period between planning and implementation. Research must also be done to locate creative ways to obtain necessary resources. (Responsible entities include: local, state and federal governments and others.)*

Disability populations impacted by the issue and how they are impacted:

Consumers, family members, providers and legislators will be limited in the educational initiatives they can initiate and complete due to a lack of funding or funding availability.

Challenges:

1. Cuts in existing funding
2. Identifying and securing private funding
3. Identifying and securing unused government funding
4. Demonstrating the necessity of education for transition and prevention
5. Failure to implement already existing responsibilities for education under the Virginia Code
6. Lack of availability of local and CSB/DSB funds
7. Need for funding for Olmstead education for all providers
8. Lack of funding for educating providers

9. Lack of prioritization of current allocations to include education -- specifically prevention and transition

Recommendation and rationale for selecting the recommendation:

- EdVII.1. The Olmstead Task Force should appoint someone to research available funding for Olmstead education.

It will require a major campaign on many levels to educate our state regarding the Olmstead plan, to say nothing of its implementation. Although many things can be done inexpensively, it will cost money. Those who work on this process need to know how much is available and where.

ISSUE VIII: CONFLICT AMONG DISABILITY GROUPS

DESCRIPTION OF THE ISSUE: *Any conflict among disability populations may hinder educational opportunities. Prejudice and misunderstanding, coupled with difficulty in communicating among various disability groups (for example, between individuals who are deaf and those who are blind), make educational initiatives more difficult.*

Disability populations impacted by the issue and how they are impacted: Conflicting and competing needs are inherent among all populations in general; this is especially true when multiple groups (i.e., disability populations) are attempting to secure limited funding (local, state and federal) for their specific disability population.

Challenges:

1. Need for inter-disability cooperation and communication
2. Difficulty in communication
3. Prejudice against unfamiliar disabilities

Recommendations and rationale for selecting the recommendations:

- EdVIII.1. Continue the issue teams for at least five years.

The Teams have demonstrated the ability to increase cross-disability understanding.

- EdVIII.2. Once the Olmstead Plan is completed, hold a statewide cross-disabilities conference to explain and discuss all aspects of it.

This would not only inform many people about the Olmstead Plan, but it could provide the impetus for more communication between people with different disabilities.

ISSUE IX: LACK OF KNOWLEDGE OF ALL DISABILITIES

DESCRIPTION OF THE ISSUE: *Olmstead planning is necessarily cross-disability; however, consumers, family members and providers often understand only the disability group they represent or with which they work. Without knowledge of the needs of all disability groups, it is difficult to create plans and initiatives that benefit all disability populations. (Responsible entities include all populations.)*

Disability populations impacted by the issue and how they are impacted: No one population can understand everything there is to know about all other populations. Each disability population will have to work to understand the important needs of each disability population involved in the planning process.

Challenges:

1. Lack of professional training opportunities and informal education
2. Lack of trainers with disabilities
3. Lack of education for people of all ages

Recommendations and rationale for selecting the recommendations:

EdIX.1. Create a statewide library of disability-related resources.

There are hundreds of people who need information on various disabilities and, as the Olmstead Plan brings more people with disabilities into the community, the need will become still greater. Likewise, there are hundreds of excellent books, videos and magazines available on all disabilities and on disability issues generally. The problem is that there is no systematic way of bringing them together. A library would do that.

EdIX.2. Create a statewide list of available resources and where they can be located for general distribution.

This would be a very inexpensive way of letting people know what is available and how to acquire it. It would also get lots of people talking to each other and cooperating.

EdIX.3. Train people with disabilities as conveners of workshops on the Olmstead Plan and other disability-related subjects and enable them to travel around the state.

How transforming would it be for the average person to be taught a class by someone who, without the kind of community based support Olmstead provides for, would be living in a nursing home and not able to work?

EdIX.4. Establish a web-based course on general issues related to disability with links to other courses and other information resources.

In newly integrated communities, many people may work with people with disabilities for the first time, or work with new disabilities. This would be an easy and systematic way to give them information.

ISSUE X: COMPETING NEEDS OF DISABILITY GROUPS

DESCRIPTION OF THE ISSUE: *All disability organizations and agencies serving people with disabilities struggle to acquire sufficient resources, and many fear sharing such resources. An Olmstead Plan can be successful only if all disability groups cooperate with one another. (Responsible entities include: agencies on all levels and disability organizations.)*

Disability populations impacted by the issue and how they are impacted:

Consumers, family members, providers and legislators must address and compromise or prioritize the various needs of all disability populations involved in the Olmstead planning process.

Challenges:

1. Need for cooperation between and among disability organizations
2. Lack of understanding of others' situations

Recommendations and rationale for selecting the recommendations:

- EdX.1. Encourage cross-disability collaborations, building on existing disability organizations.

It is much easier to build on the strength of groups devoted to specific disabilities that already exist, than to start from scratch in the difficult task of building inter-disability bridges.

ISSUE XI: LACK OF INCLUSION OF PEOPLE WITH DISABILITIES IN PLANNING GROUPS

DESCRIPTION OF THE ISSUE: *In Olmstead planning, as well as in all planning for independence, a greater number of people with disabilities need to participate. Individuals with disabilities are the ones best able to evaluate the services they receive. These individuals are also in the best position to advocate for what they want and need and to influence others to make their wishes known. (Responsible entities include: local and state governments, local and state agencies and boards.)*

Disability populations impacted by the issue and how they are impacted: Olmstead planning and implementation will affect a multitude of different agencies and organizations, including non-disability groups. It will become most important for

disability populations to be actively involved in planning groups outside of the disability populations; however, these groups will likely be unaware of Olmstead and will need to be educated on inclusion of disability populations.

Challenges:

1. Lack of notice and information about hearings and meetings
2. Lack of recruitment of people with disabilities for government boards
3. Lack of reasonable accommodations, especially transportation
4. Lack of consideration of the hour and location of meetings

Recommendations and rationale for selecting the recommendations:

EdXI.1. Encourage people in all levels of government to appoint more people with disabilities to boards and planning groups that concern issues important to them.

People with disabilities know what they need and care that it should get done. They will offer a fresh viewpoint to many of the people they work with, and their presence will help generally to integrate them and others like them into community life.

EdXI.2. Encourage the governor to appoint people with disabilities to state boards other than human services.

People with disabilities are interested in all aspects of life. If we are to become an integrated society, they must be included in all aspects of deliberation.

EdXI.3. Encourage all conveners of planning meetings to send timely, well-publicized notices in advance.

It is often harder for a person with a disability to plan attendance at a meeting. Also, for those with communication problems, it may take longer to get the notices.

EdXI.4. Encourage all meeting planners to give appropriate consideration to reasonable accommodation for those who need it.

If people with disabilities feel that they cannot expect reasonable accommodation, they may choose not to attend, rather than struggle without it or be made to feel unwelcome when they ask for it. Besides, reasonable accommodation is the law.

EdXI.5. Encourage meeting planners on all levels to consider the needs of disabled participants when choosing time and place.

Lack of accessibility or lack of ability to schedule assistance at the necessary time may result in lack of attendance by people with disabilities. Also, it is important in planning to consider when public transportation runs.

EdXI.6. Encourage meeting planners to assist with providing transportation when that is necessary.

Sometimes a person with a disability simply has no transportation that would make it possible for him or her to participate regularly in meetings. In that case, if the group planning the meeting is serious about consumer attendance, it may need to consider giving a hand in the way of car pooling or hiring a bus.

ISSUE XII: LACK OF VALID CONSUMER FEEDBACK ON SERVICES

DESCRIPTION OF THE ISSUE: *Surveys and consumer feedback forms are often not designed for easy responses and may not even be designed in a form that accommodates consumers with various disabilities. Too many consumers do not know their rights to question or ask for a change in the services they receive. Also, consumers may not have the opportunity to talk or write confidentially when giving feedback on services. (Responsible entities include: state and local governments and agencies and others.)*

Disability populations impacted by the issue and how they are impacted:

Consumers, family members, providers and legislators must work to address the need for more valid feedback regarding the services provided to consumers. It will be difficult for providers and legislators to adapt and improve services if accurate and appropriate feedback is not obtained.

Challenges:

1. Lack of meaningful accessible surveys
2. Lack of sufficient education on rights under Olmstead
3. Lack of opportunity for confidential consumer feedback

Recommendations and rationale for selecting the recommendations:

EdXII.1. Make efforts to improve the validity and reliability of consumer satisfaction feedback instruments.

Many consumer satisfaction feedback instruments are unnecessarily long and complicated, and they do not always get at the real questions of concern. Much more research is needed to develop practical, usable instruments that can truly tell us the level of satisfaction generally, as well as the strengths and weaknesses of a program.

EdXII.2. Establish statewide teams of people with disabilities to survey consumer satisfaction and report the results.

Many people with disabilities need help in filling out questionnaires or, for other reasons, feel that their answers may not be confidential. The fear of retaliation may prevent some

people from expressing their real feelings. An objective team of people with disabilities could go far toward solving this problem.

EdXII.3. Conduct careful follow up studies of people in transition.

Transition is not only a critical time to ensure that individuals get the extra help they may need, but it is an excellent opportunity for evaluating the success of various programs. This would not only provide an additional source of information about consumers and their needs, but also safeguard their welfare.

ISSUE XIII: COMPETITION BETWEEN AND AMONG AGENCIES

DESCRIPTION OF THE ISSUE: *Agencies naturally struggle to maintain their budgets and responsibilities. This means that substituting new services for old, or providing new services which may seem duplicative, is bound to be seen by some as a threat. Agency competition is often a major source of misinformation and may be a barrier in any attempts to educate.*

Disability populations impacted by the issue and how they are impacted:

Consumers, family members and providers must work to identify the natural competition that exists between and among agencies that compete for limited funding. This competition is especially notable during fiscally strained times.

Challenges:

1. Fear of losing fiscal resources to others
2. Self preservation – competition in providing best services to consumers
3. Lack of cross-secretariat education
4. Lack of team work
5. Lack of serving customers as a collective responsible entity
6. Differing viewpoints about what constitutes good services
7. Duplication of services
8. Fear of lost prestige or power
9. Fear of loss of jobs through consolidation of services
10. Too many agencies dealing with disability
11. Lack of a level playing field
12. Lack of win-win philosophy
13. Lack of agreement on priorities
14. Lack of mutual respect
15. Lack of identified common values
16. Lack of balanced system within Olmstead guidelines

Recommendations and rationale for selecting the recommendations:

EdXIII.1. The state government should provide fiscal incentives for agencies to work together.

Since fear of the loss of funding is one of the sources of conflict, fiscal incentives to avoid it should certainly minimize the problem.

ISSUE XIV: CONFLICTING MESSAGES

DESCRIPTION OF THE ISSUE: *People often receive conflicting messages due to poor communication between groups dispensing information, misunderstandings of law and policies and conflicting views regarding the capacity of individuals with disabilities. These conflicting messages may hinder the educational process because time is spent clarifying misunderstandings.*

Disability populations impacted by the issue and how they are impacted: All populations must work to communicate clearly during this process. Since this is the first time all disability populations have joined to work on such a large plan, consensus must be utilized to develop clear messages and avoid misunderstandings.

Challenges:

1. Lack of understanding of self-determination by government
2. Lack of appreciation of gifts and talents of persons with disabilities
3. Differing goals of messengers
4. Conflicting interpretations of difficult laws and regulations
5. Written communication may be misinterpreted and communicated to other incorrectly
6. Agencies may interpret state government practices as being barriers to success
7. Use of complicated nomenclature
8. Goals, objectives, and priorities not clearly focused
9. Lack of knowledge of all possibilities
10. Case workers' discrimination when explaining choice
11. Confusion about disability definitions

Recommendations and rationale for selecting the recommendations:

EdXIV.1. Encourage interagency collaboration in the provision of services, especially on the local level.

There are many activities, such as public education programs, that can be better done by several small agencies working together than by any one of them alone. At the same time, greater interagency understanding is likely to result from their working together.

ISSUE XV: LACK OF COMMON LANGUAGE

DESCRIPTION OF THE ISSUE: *Different governmental departments, agencies and educational disciplines use different terminology. Various languages and terms can cause confusion and misunderstanding and hinder the educational process. (Responsible entities include: state and federal governments.)*

Disability populations impacted by the issue and how they are impacted: Different disability populations utilize differing terminologies to describe various aspects of their specific disabilities and populations. There is not a universal disability language utilized by all disability populations; therefore, many terminologies and words have multiple meanings when considered by various disability populations.

Challenges:

1. Isolated communities
2. Lack of programs to cross-fertilize and build common ground
3. Lack of easily accessible definitions from various fields
4. Acronyms and abbreviations may vary by agency and care type
5. Consumers may not understand health care terms and uses
6. Too many interpretations of titles such as 'Olmstead Plan'
7. Lack of information in multiple languages
8. Different terminology from different disciplines

Recommendations and rationale for selecting the recommendations:

EdXV.1. Support the glossary of terminology that is being planned by the Department of Medical Assistance Services (DMAS) in any way possible.

This would be a first step in helping people from differing disciplines and agencies to understand each other's terminology.

ISSUE XVI: TRANSPORTATION/TRAVEL TO MEETINGS

DESCRIPTION OF THE ISSUE: *The first barrier to any education of families and consumers is getting a group of them together in one place. Poverty and lack of driving skills make people dependent on public transportation, which does not exist in many areas of the state. Because of insurance rates and maintenance costs, the provision of transportation by private agencies has become more and more difficult. When public transportation is provided, it is often unreliable or limited to daytime hours. This means that the providers of any educational program have to choose between reaching people who work and reaching those who rely on public transportation--a difficult choice. This is a major barrier to the dissemination of information in most of the state. If a wide diversity of people from lower and middle classes are to be contacted or involved in a planning process, it may be necessary to consider paid transportation and/or stipends to*

*compensate people who work in the same way we compensate jury members.
(Responsible entities include: all levels of government.)*

Disability populations impacted by the issue and how they are impacted:

Consumers, family members and providers are frequently confronted with transportation and travel barriers. As transportation is a limited resource, travel to meetings is often considered unnecessary or secondary to meetings basic needs, such as medical or dietary, and is difficult to obtain.

Challenges:

1. Lack of fiscal resources to support transportation
2. Limited availability of transportation during off-working hours
3. Lack of public appreciation of the importance of public transportation
4. Scattered population in rural areas
5. Public transportation lacks necessary adaptations for individuals with disabilities
6. Appropriate public transportation may be limited and inconsistent
7. Lack of meetings close to audience
8. Lack of timely meeting notices
9. Lack of appropriate transportation information and funds
10. Difficulty with scheduling meetings convenient to consumers

Recommendations and rationale for selecting the recommendations:

EdXVI.1. All levels of government, as well as private providers of transportation, should explore possibilities of additional funding to improve transportation for people with disabilities.

Transportation requires greater funding privately and all on government levels.

ISSUE XVII: SIZE AND GEOGRAPHY OF STATE

DESCRIPTION OF THE ISSUE: *Because the state is not only large, but also is separated into regions by natural barriers, the flow of information from one region to another is often impeded. Also, because the regions are so different, their educational needs and the required strategies to meet those needs may be different. The extremely rural areas, mountain communities, and urban areas, including suburban areas near Washington, D.C., often have little in common with one another. These facts not only complicate any effort at education on a statewide basis, but also make it more expensive.*

Disability populations impacted by the issue and how they are impacted: Because of the size of Virginia and its natural barriers, information flow from one area of the state to another is often impeded. In addition, the educational needs and required strategies to meet those needs vary widely. The variety of needs across Virginia requires a variety of

educational initiatives, thus increasing the cost for statewide educational initiatives related to Olmstead.

Challenges:

1. Lack of cross-regional communication
2. Separation of regions
3. Differing needs of rural and urban populations
4. Agency operations may vary by region
5. Diversity of needs
6. Lack of teleconferencing equipment and opportunities

Recommendations and rationale for selecting the recommendations:

EdXVII.1. Include more representation of people with disabilities from all regions in all planning processes.

Even though the regions of the state may differ widely, people with disabilities will still have some common needs that can be addressed across regional lines.

EdXVII.2. Establish regional and statewide town meetings using teleconferencing and video conferencing.

This modern technology can bring together people who are hours apart and cost much less in the process.

EdXVII.3. Use online chat rooms could become focus groups.

This is an efficient and inexpensive way of involving a diverse group of people from around the whole state in a conversation.

ISSUE XVIII: FEAR OF CHANGE

DESCRIPTION OF THE ISSUE: *Inertia and lack of imagination often stand in the way of new ideas and new programs. Many people feel threatened because they see the challenges but fail to see the benefits. Any successful educational program will have to openly confront and deal with these fears and apprehensions.*

Disability populations impacted by the issue and how they are impacted: Fear of change is natural and must be addressed by all populations. Fear of change inhibits creativity and imagination in identifying new ideas and programs.

Challenges:

1. Lack of education of families and the public about the benefits of change
2. Lack of imagination
3. Fear among service providers about additional work and new responsibilities
4. Agencies fear structure will change
5. Agencies fear changing reimbursement for projects
6. Lack of clear understanding of rationale for change
7. Lack of motivation to change or acceptance of it
8. Exclusion of stakeholders in change process

Recommendations and rationale for selecting the recommendations:

EdXVIII.1. Promote opportunities for understanding the positive aspects of change.

People sometimes fear change because they have not thought through all of its possibilities. If they can be helped to do that and shown that change may have unexpected advantages, they may become less fearful.

EdXVIII.2. Reward imagination.

The more creative response to change can be rewarded and showcased, the less threatening it is likely to seem.

EdXVIII.3. Examine best practices in Olmstead Plans from other states.

If people can see examples of plans that have worked elsewhere, they are likely to be less apprehensive.

EdXVIII.4. Give consumers who have been successful at being independent the opportunity to educate other consumers and their families about the possibilities.

Consumers who have been successful at being independent should have the opportunity to educate other consumers and their families about the possibilities.

C. REPORT OF THE EMPLOYMENT TEAM

Team Chair: Karen Tefelski

Team Recorders: Susan Davis Payne/Karen Tefelski

Agency Convener: Susan Davis Payne, Department of Rehabilitative Services (DRS)

Comprised of members of the Olmstead Task Force and other representatives from the community with personal and professional experience in the provision of services to individuals with disabilities, the Employment Issues Team (EIT) sought to broaden its knowledge and experience base by including consumers, family members, and service providers as consultants. With a focus on viewing employment as an issue of importance crossing disability lines, information and recommendations have been sought to date from representatives with experience and expertise in the areas of Deafness, Mental Health, Autism, Substance Abuse, Developmental Disabilities, Brain Injury, AIDs, Learning Disabilities, and Mental Retardation. In preparation of the final EIT report, further work of the team will be enriched by seeking input from consultants with understanding of barriers experienced by individuals with other physical, sensory, and cognitive disabilities.

Vision and values:

The true measure of integration in and access to living in the community is an individual's choice and opportunity to work. The dignity, responsibility, and economic independence resulting from gainful employment is the most effective way of reducing dependence on public benefits, enhancing self-reliance, changing attitudes, and promoting full community integration of individuals with disabilities.

ISSUE I: SYSTEMS CAPACITY BUILDING

Challenges:

1. Service infrastructure and design: While there are several initiatives and programs that address varying levels of employment readiness, training, and placement for individuals with disabilities, there is no coordinated effort to strengthen existing infrastructure or design a system that integrates services in a manner that is consumer-friendly and expands service capacity. The existing service system is very complicated and far-reaching. Agencies such as the Department of Rehabilitative Services (DRS), the Department of Medical Assistance Services (DMAS), the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS), and the Department of Social Services (DSS) all have employment-related service options for individuals with disabilities, and each agency has a different point of entry for services. Subsequently, services may be duplicative and confusing. At this time there is no system in place that facilitates or mandates

coordination between the institution staff and community providers to link consumers with employment support prior to discharge, much less at entry into institutions or community services. Employment is not considered a service need, even though many individuals with disabilities leaving institutions have employment as an ultimate goal. There are unclear goals and expectations, funding sources, and strategies to meet the employment needs of individuals with a serious mental illness.

2. Federal program issues.
3. Appropriate targeting of services.
4. Role of providers and provider availability: Virginia lacks capacity to provide employment services to adults with a serious mental illness in accordance with the evidence-based supported employment/individual placement and supports model. For individuals who reside in rural areas, very few employment services options are available. Many are forced to settle for facility-based work in non-integrated settings. With appropriate incentives (for example, appropriate reimbursement rates), many providers would be able to develop services in these dramatically under-served regions of the Commonwealth.
5. Availability of community services and supports.
6. Service coordination among institutional and community providers: At this time there is no system in place that facilitates or mandates coordination between the institution staff and community providers to link consumers with employment support prior to discharge much less at entry into institutions or community services. Employment is not considered a service need, even though many individuals with disabilities leaving institutions have employment as an ultimate goal.
7. Linkages with other service systems
8. Monitoring and oversight.
9. Data/information system issues.

Options:

EmOpI.1.a. Initiate cross-agency policies, procedures and training programs to remove institutional bias from the service delivery system.

Removing institutional bias is advantageous because community living and employment is much less costly than institutional placement.

EmOpI.1.b. Institute meaningful tax credits for employers and employees using Personal Assistance Services as a means to support employment for employees with disabilities.

Personal Assistance Services would become more cost-effective for employers and employees purchasing the services.

EmOpI.2. Create incentives for employment service provider organizations to expand services in under-served areas.

This would expand employment opportunities for individuals with disabilities.

ISSUE II: SERVICE CAPACITY

DESCRIPTION OF THE ISSUE: *Service Capacity is a large over-arching issue encompassing any number of sub-issues, including job coaching, placement, training, follow-along and worksite accommodations (including personal assistance services and assistive technology and self-advocacy skills development). Service capacity, as it relates to individuals with disabilities seeking self-sufficiency through employment, refers to the Commonwealth's ability to contain, access funds, and have available services that indeed support an individual's choice and opportunity to work. At the present time, services available to, and accessible for, individuals with disabilities are fragmented and often inadequate to facilitate individuals' desires to live and work in the community.*

Background and data: For many Virginians with physical, sensory, or cognitive and mental disabilities, employment can become a reality only through the provision of goods and services that will help offset functional limitations caused by the nature of the disability and/or accompanying condition. Deficits in service capacity are numerous and affect individuals across disability lines and social and economical status. Having heard from several people with disabilities, parents, disability professionals, and consultants, the EIT has become acutely aware that entry into the service delivery system where gainful employment is the ultimate goal is difficult at best. Developing an understanding of how to enter into and access appropriate goods and services is challenging, especially when various public and private providers of services are uninformed or confused about the array of services available. Additionally, individuals who have newly acquired disabilities or who have never entered into the public arena of service provision have no clear guidance about who to contact or how to begin the process of seeking employment. Individuals with disabilities, family members, advocates, and service providers at the state and local level consistently report that employment supports are inadequate to meet the needs of an ever-growing number of individuals with disabilities who choose employment as the means to self-sufficiency and community inclusion.

Relationship between the issue and current laws, regulations and policies:

Federal: Rehabilitation Act of 1973
 Individual with Disabilities Education Act

Current programs and initiatives addressing the issue:

1. *Vocational Rehabilitation Services* administered by the Virginia Department of Rehabilitative Services (DRS): As mandated by Title I of the Rehabilitation Act of 1973 and utilizing a combination of Federal and state funds, delivery of goods and services are designed to assist eligible consumers with disabilities who seek an employment outcome through the provision of an Employment Plan.
2. The *Virginia Initiative for Employment Not Welfare (VIEW)*, administered by the Virginia Department of Social Services (DSS): Initiated in 1995 as a part of nationwide Welfare reform, VIEW is the employment component of the Temporary

Aid for Needy Families (TANF) program. Entrants undergo initial assessment, case management, intensive rehabilitation, treatment and support services, supportive work experience or other work programs, and eventual unsubsidized employment with transition support after leaving TANF.

3. *Work Incentives Training and/or Benefits Counseling*, administered by Benefits Planning Assistance Outreach Programs: Provides counseling, guidance, and training regarding work incentives.
4. *Benefits Planning*, administered by Benefits Planning and Outreach Programs, and *Assistance Outreach and Advocacy Counseling and legal services* offered by the Virginia Office of Protection and Advocacy (VOPA) regarding adverse Social Security Administration decisions pertaining to disability claims.
5. *Personal Assistance Services*, administered by the Department of Rehabilitative Services (DRS): Assistance with activities of daily living, which includes help with activities unrelated to the actual accomplishment of work tasks in the work place.
6. *Medicaid Waiver Services*, administered by the Virginia Department of Medical Assistance Services (DMAS): A wide array of services including, but not limited to, personal assistance services and supported employment, through the Mental Retardation, Consumer-Directed, and Development Disabilities Waivers.
7. *Workforce Investment Act and One-Stop*, administered by the Virginia Employment Commission (VEC).
8. *Social Security Act initiatives*, administered by the Social Security Administration.

Disability populations impacted by the issue and how they are impacted: Individuals representative of all types of disability populations are prevented from participating fully in programs and services due to lack of adequate funding (or historical under-funding), coordination and understanding of work among agencies and providers. Additionally, there is a significant lack of collaboration between and among state, local, public and private providers of services, often causing confusion for individuals with disabilities seeking information and guidance regarding work preparation and obtaining and maintaining employment short and long-term.

Challenges:

1. Service infrastructure and design:
 - No mechanism exists to continue BPAO activities after the Social Security Administration grant ends in June 2006.
 - There is no universal access to services.
 - Current job placement and job coaching services have a definite institutional bias.

- The existing rate structure creates a disincentive for providers who wish to create community-based (as opposed to facility-based) employment opportunities for customers with disabilities.
2. Federal program issues:
- Currently, personal assistance services are not available in all Medicaid Waivers as a workplace support.
 - Vocational rehabilitation service options are not interpreted consistently statewide by state staff responsible for providing services or by private providers vending services.
 - Medicaid State Plan Option Mental Health Services exclude the provision of vocational and employment services.
 - For certain populations (for example, mental health and substance abuse), long-term employment support services are not available for persons with disabilities that require ongoing support services to maintain employment.
 - Funding of supported employment through DMAS Medicaid Waivers is inadequate and does not reflect the cost of providing the community-based service.
 - Funding of Job Coaching through the Department of Medical Assistance Services (DMAS) has an institutional bias.
 - Currently, rates are so low that many providers cannot consider developing new services to meet community demands. Job Coaching rates through the Department of Rehabilitative Services (DRS) are higher than other agencies, but offer few incentives to providers to deliver this service in the community.
3. Appropriate targeting of services:
- Lack of specialized vocational services and long-term follow along for TANF recipients with disabilities.
 - Significant lack of consumer driven job development, situational assessment, job placement and development, job coaching, and resources for all Virginians with disabilities, especially those with complex needs. This is particularly challenging for individuals with autism, brain injuries, dual diagnosis, mental illness or those individuals who are medically fragile.
 - Individuals with disabilities are often not provided the opportunity to choose the range of supports they feel they need, or the type of job they would prefer. All choices and decisions about work and supports should be individualized—based on the individual’s preferences, strengths, and experience.
 - Lack of access to or knowledge of assistive technology and funding sources for assistive technology as a support for individuals with disabilities seeking employment. This includes limited knowledge among providers, employers, consumers, and other institutional and community providers.
 - The Community Services Board mental health system focuses almost exclusively on psychosocial rehabilitation reimbursed by Medicaid (as opposed to supported employment funded by DRS). See DMAS Community Mental Health Rehabilitative Services Manual, Chapter IV, Covered Services and Limitations, page 11, revised 5/01/2002). It is unlikely that individuals with a serious mental illness are asked at intake to the Community Service Board about their interest in employment as recommended by the Evidence-Based Practice.

4. Role of providers and provider availability:

- The long-term effect of inadequate provider reimbursement rates has affected the availability of qualified providers and subsequent statewide access to services for people with disabilities.
- The current workforce crisis in the human services industry is exacerbated by Virginia's historical under-funding of services and long-term low reimbursement rates, which affect the ability of providers to recruit and retain qualified professional staff.
- Lack of providers of services at the community level to facilitate the use of services available under the Consumer-Directed and Developmental Disabilities Waiver.
- Lack of financial incentives/clear reimbursement model has inhibited provider and service system development that would be maximally responsive to mental health target population.
- Lack of providers to provide individualized services to serve specialized and unique populations (for example, autism and dual diagnosis.)
- Benefits counseling and legal assistance may be available through private law firms, but can be very costly unless offered on a pro-bono basis.

5. Availability of community services and supports:

- Lack of adequate job placement, job development, and long-term follow-along supports for individuals living with HIV AIDs and other disabilities. (i.e., medically fragile).
- Lack of vocational services and wrap around supports for individuals in recovery from alcohol and drug dependence.
- Lack of services being developed for individuals with mental illness because of the stigma and low expectations among employers and providers.
- Assistive Technology (AT) supports for work are restrictive.
- Research suggests natural supports are lacking for individuals with serious mental illness. For further details see: www rtc.uwstout.edu/research/findings.html.
- There is a lack of adequate and accessible transportation for people with disabilities who want to and can work.

6. Service coordination among institutional and community providers:

- At this time there is no system in place that facilitates or mandates coordination between the institution staff and community providers to link consumers with employment support prior to discharge much less at entry into institutions.
- Employment is not considered as a service need, even though many individuals with disabilities leaving institutions have employment as an ultimate goal.
- Current practices focusing on clinical/case management issues, stigma regarding mental illness and other disabilities lead to low expectations of individuals with mental illness.

7. Linkages with other service systems:

- All service systems retain elements of stigma against individuals with disabilities.
- Transition services to ensure the move from school to work or post-secondary training often does not begin early enough to facilitate a student's access to the needed supports.

- Benefits Planning and Assistance services are not readily available in school systems for students with disabilities and their families.
- The Evidenced Based Practice of Supported Employment clearly indicates an integrated team approach to coordinate a full range of employment, case management and treatment services for individuals with mental illness.

8. Data/information system issues: Employment as an outcome is not measured with consideration of financial incentives in order to establish employment as a priority.

Options:

EmOpII.1.a. Establish cross-agency policies, procedures, and implementation plans that include employment specialists on discharge teams prior to discharge of individuals from institutions to the community.

Employment Specialists on discharge teams and community-based services intake and clinical treatment teams increase the level of expertise of the team and provide consumers with employment support prior to discharge and upon entry into the community.

EmOpII.1.b. Establish a mechanism to continue BPAO projects after SSA grant contract expires.

BPAO projects currently in place have established competencies that could be used as models by other vendors in Virginia.

EmOpII.1.c. Establish incentives for law firms to encourage benefits counseling and legal assistance on a pro-bono basis.

This would increase the number of providers for benefits counseling and legal assistance.

EmOpII.1.d. Consider establishing rates to providers for community-based services equal to those paid to institutions.

Establishing comparable rates of pay would make it more profitable for providers to offer community-based services.

Note: Each option noted above increases individual employment support choice, leading to more consumer-driven employment options. Each option described also has a financial cost.

EmOpII.2.a. Expand Medicaid waiver services in all waivers to include Personal Assistance Services (PAS) as an option that can be used in the workplace for individuals with disabilities.

This would increase the options of individuals with disabilities to receive PAS on the job for non-work related tasks, such as assistance with meals and restroom.

EmOpII.2.b. Improve communication using assistive technology and traditional methods among vocational rehabilitation programs within the Department of Rehabilitative Services (DRS), private vendors of service, and individuals with disabilities to facilitate access to appropriate vocational rehabilitation services.

This would increase understanding of services and options among state agency staff, vendors and individuals with disabilities, ultimately leading to provision of employment services in a more timely and concerted manner. Individuals would enter into gainful employment more quickly.

EmOpII.2.c. Expand Medicaid State Plan Option to include employment-related services such as Personal Assistance Services, assistive technology, job coaching, and job placement for Medicaid eligible individuals with disabilities.

This would increase choices for individuals with disabilities who choose to work.

EmOpII.2.d. Encourage the Department of Rehabilitative Services (DRS) to use the ESO capacity-building grant program to offer incentives for providing community-based services.

This would make the provision of community-based services profitable to providers, thus increasing access to consumers, especially in rural areas.

EmOpII.3.a. Establish adequate rates of reimbursement for job coaching, placement, training, and follow along to be utilized by all state agencies purchasing these services from private providers.

Equalizing the rate of reimbursement for providers ensures greater access to services for individuals with disabilities because of the increase in numbers of providers willing to provide the service.

EmOpII.3.b. Develop an expectation that all providers maintain a standard level of competence and expertise for the provision of community-based services, including the provision of workplace supports.

EmOpII.3.c. Implement a standard for both public and private providers that services be provided using a consumer-directed model where individuals with disabilities take an active part in job exploration, development, and maintenance activities.

EmOpII.3.d. Develop minimal competencies to ensure that both public and private providers have appropriate expertise to provide Benefits Planning Services.

Individuals with disabilities are more likely to become invested in the employment process when they take an active role in accomplishing tasks related to job placement and follow-along using a consumer-directed model.

- EmOpII.4.a. Include Vocational Assessment and services, benefits planning, and wrap-around in discharge planning.
- EmOpII.4.b. Include employment specialists on discharge planning teams.
- EmOpII.4.c. Include employment specialists in treatment planning and implementation to establish relationships with individuals with disabilities prior to discharge.

Individuals with disabilities preparing for and re-entering the community following institutionalization will have the benefit of planning for employment in advance of deinstitutionalization.

For all individuals with disabilities seeking to enter or re-enter the workforce, establishing relationships with employment specialists increase the likelihood of success in obtaining and maintaining employment.

- EmOpII.5.a. Expand transition services to students with disabilities and their families at the school and vocational rehabilitation level to include benefits planning services. Add this service to the student's Individualized Education Plan as a required service.
- EmOpII.5.b. Establish cooperative agreements with public school systems and state agencies to facilitate utilization of Job Coaching as a means of gaining work experience before the student exits from high school.
- EmOpII.5.c. Begin transition services for students with disabilities in the freshman year, even if the only service is the provision of technical assistance.
- EmOpII.5.d. Implement the Evidenced-Based Practice of Supported Employment, which clearly indicates an integrated team approach to coordinate a full range of employment, case management and treatment services is needed.

Students and their families would have an understanding of various benefits issues prior to transitioning from school into the workforce. Students with disabilities would have the opportunity to gain experience in the workplace prior to graduation increasing student employment. Students with disabilities, service providers, parents and teachers would have a better understanding of barriers to transition and employment and can plan accordingly. Additionally, the earlier services begin, the better the employment outcome.

Recommendations and rationale for selecting the recommendations:

EmII.1.a. DMHMRSAS, in collaboration with supported employment providers, should take the lead in identifying and solving the financial and organizational barriers to implementing the Evidence-Based Practices of Supported Employment for adults with a serious mental illness.

This would establish clearly understood financial guidelines of existing financial support that may be available for SE as an EBP for adults with a serious mental illness.

EmII.1.b. DMHMRSAS, DRS, and DMAS, in coordination with employment services organizations, should collaborate and develop a document and joint training initiative that clearly identifies and articulates the employment related services and supports that could be paid by vocational rehabilitation (VR) and community support services for selected supported work activities that would be allowable for Medicaid reimbursement.

This would overcome funding fragmentation.

EmII.1.c. DMHMRSAS, DRS and DMAS should also explore and coordinate existing resource allocation to be certain that federal reimbursement is maximized.

This would maximize available funding.

EmII.2. Add employment specialists on initial screening and discharge/transition planning teams at institutions and nursing facilities.

This would provide the benefit of an employment specialist in considering services necessity and options in the community.

ISSUE III: FINANCIAL DISINCENTIVES

DESCRIPTION OF THE ISSUE: *In Virginia, a review of the financial thresholds that determine eligibility for services for individuals with disabilities demonstrates how participating in gainful employment can impact access to, or maintenance of, benefits or other resources that support an individual's ability to live and work in the community. In all areas, from housing to health insurance coverage to personal care, substantial financial disincentives, actual or perceived, affect individuals with disabilities who seek self-sufficiency through competitive or community-based employment. Often these disincentives cause individuals to lose the services and supports they require to maintain employment and economic independence. Largely due to dated, complex and conflicting federal, state, and local disability policies, financial disincentives also negatively impact family members and service providers. To assist individuals with disabilities in participating fully in communities across the Commonwealth, education of the public*

about disability policies, across agencies and programs, with an emphasis on advancing economic empowerment through employment is imperative.

Background and data: Over the last 15 years, federal and state laws have changed, increasing the ability of people with disabilities to seek self-sufficiency and community living. New employment advancement programs and funding sources have been developed in an attempt to respond to changes in the law as other, more traditional, models have also continued. Policies have been modified piecemeal as each new change in the law occurs, resulting in instances where policies conflict across agencies or programs. Consequently, the system of services and benefits has become so complex that consumers, family members, providers and, often, state agencies are unable to accurately interpret the very laws and policies intended to facilitate integration of individuals with disabilities into the workplace. Financial disincentives are the unintended consequences of this complexity of conflicting policies across programs and agencies.

In Virginia, as in other states, many individuals with disabilities have learned that steps toward self-sufficiency may lead to serious personal and financial loss of critical benefits and other resources. In many instances, individuals experience the loss of the basic benefits needed to live in the community including, but not limited to, services and supports related to health care, personal assistance services (PAS), housing, transportation, mental health care, and medical management. Individuals may lose Medicaid Wavier services, food stamps, and other services and benefits driven by financial eligibility criteria. Social Security benefits overpayment and required repayment are also problematic. Experientially, individuals with disabilities and their service providers know that, when the individual's earned income increases, critical family services and supports, including funding streams accessed through federal, state, and local governments, may decrease and even cease. It is often with great trepidation that individuals with disabilities and their providers consider full time competitive employment as a goal under these circumstances.

Relationship between the issue and current laws, regulations and policies:

A number of specific federal, state, and local program policies have been identified as conflicting, overly complex and/or underutilized in Virginia including:

Federal Policies:

Federal Work Incentives for SSI & SSDI--A number of work incentives exist to assist many people with disabilities to be employed and earn significant income. However, work incentive programs are often complex, time consuming and difficult for individuals to understand and complete the necessary paperwork independently. In addition, many providers, both public and private, do not have a thorough understanding of all the incentives available to their clients. These federal work incentives include Trial Work Periods, Extended Period of Eligibility, Impairment Related Work Expense, Section 301, Blind Work Expense, Student Earned Income Exclusion (SEIE), 1619a & 1619b, Impairment Related Work Expense (IRWE), Property Essential for Self Support, Subsidies, and Plan for Achieving Self Support (PASS).

Programs to Achieve Self - Sufficiency (PASS) – PASS is an income and/or resource exclusion that allows a person with disabilities to set aside income and/or resources for an occupational objective. PASS can help an individual establish or maintain SSI eligibility and can also increase or help maintain the individual’s SSI payment amount as the person gains the capacity for self support. Unfortunately, many individuals with disabilities and their families, as well as public and private providers, have little knowledge about this invaluable work incentive.

Supplemental Security Insurance (SSI) 1619b Program--This program allows individuals receiving SSI who go to work and no longer receive a cash payment due to earned income, to retain Medicaid benefits as long as their income remains below Virginia’s threshold limit of \$21,778. However, there is significant confusion at the local level regarding implementation of 1619b eligibility and benefits.

Impairment Related Work Expense (IRWE)--Certain expenses related to a person’s disability that are needed in order for the person to work can be deducted from the income reported to SSI for a reduced income calculation. Unfortunately, many people with disabilities and their families, as well as public and private service providers, have little knowledge about the benefits of this work incentive.

Individuals with Disabilities Act (IDEA)--In many instances students, parents and educators have limited awareness of the transition from school-to-work requirements mandated under IDEA (DOE report, 2002). Additionally, there is little knowledge at the local level of work incentives, adult employment opportunities, and community supports for students with disabilities in the transition process.

Employer Tax Credits--The federal government has offered tax credit incentives for employers who hire people with disabilities (Work Opportunity Tax Credit – WOTC) and for employers who hire Welfare to Work (Welfare to Work Tax Credit – WtW Tax Credit) recipients for many years. The IRS also allows businesses to take a credit for accommodations that address both “work access” and “removal of architectural and transportation barriers for new hires with disabilities” under certain circumstances. Both of these tax credits can be substantial (\$2,400-\$8,500 per year). Although most professionals in the “job placement” business are aware of these credits, many disability professionals and potential business employers are not. Coordination and additional education and outreach to employers regarding available tax incentives and the largely untapped workforce of Virginians with disabilities through the Commerce and Trade agency would be extremely beneficial.

Medicaid coverage wrap-around with private employer-provided health insurance under the guidelines of Health Insurance Portability and Accountability Act of 1996 (HIPAA)--HIPAA limits the extent to which a plan or issuer can apply a preexisting condition exclusion.

State Policies:

Medicaid eligibility - The Commonwealth has limited standard income (80% Federal Poverty Level) and resource eligibility limits (\$2000 for an individual) for Medicaid eligibility compared to many states that have higher eligibility and resource thresholds. This affects an individual’s efforts to increase self-sufficiency through gainful employment.

Medicaid State Plan Options (SPO) – The existing Medicaid SPO for individuals with serious mental illness limits reimbursement for vocational services.

Personal Assistance Services (PAS) – Currently, PAS is not an optional service under the Medicaid State Plan Option. This service is needed to help individuals with significant disabilities manage activities of daily living before, during, and after work. PAS is part of the Medicaid State Plan Option Service in many other states, and this is strongly encouraged by the federal Centers for Medicare and Medicaid Services (CMS).

Home and Community Based (HCB) Medicaid Waiver eligibility and income requirements--The state's HCB Waiver eligibility requires the waiver recipient to cover the cost of services over and above \$552, often removing any financial incentive to work for potentially thousands of existing waiver recipients. Only two out of the six HCB waiver programs in Virginia include earned income disregards for people who work (MR & DD Waivers).

HCB Medicaid Waiver employment service reimbursement rates – HCB reimbursement rates are higher for non-employment related services than for supported employment services, thereby encouraging providers to develop non-work, group day activities and discouraging supported employment service providers from becoming providers of Medicaid-funded supported employment services.

Medicaid Buy-In Program development activities - This program, when developed for the state, will significantly reduce financial disincentives to work and increased income. Because of current budgetary restrictions, the 2003 General Assembly passed legislation (HB 1822) directing the Department of Medical Assistance Services (DMAS) to develop a Section 1115 waiver to submit to the Centers for Medicare and Medicaid Services to cover up to 200 people with income not exceeding 175% of the Federal Poverty Limit. DMAS is to develop the waiver proposal and present it to the Governor and the Disability Commission by October 15, 2003, in order that the fiscal impact of a Medicaid Buy-In program can be considered in the development of the 2004-2006 biennial budget.

Department of Social Services (DSS) Assisted Living Facility Auxiliary Grants- Current regulations present a serious financial disincentive for any employment or increased earnings for people with disabilities. In addition, Assisted Living Facility (ALF) providers would benefit from extensive training regarding the importance of employment for individuals with disabilities.

Local community policies--Local policies related to co-pays for medication, counseling, employment coaching, transportation, public housing and other cost services have been found to be financial disincentives for employment. Increased earnings often eliminate incentives for career advancements or increased hours of work for individuals with disabilities because the more money earned, the higher the required contribution.

Exemptions on Temporary Aid for Needy Families (TANF)--In 1995 when TANF was initiated, the focus was to facilitate employment of able-bodied parents. However, the TANF program has evolved into providing services to "hard-to-serve" individuals, including those with disabilities. As currently administered, most individuals with disabilities do not receive employment or training services while receiving TANF. In fact, existing TANF policy inhibits individuals with disabilities from achieving self-sufficiency. Services specifically designed to assist TANF recipients with disabilities are limited. Modifications to financial exemptions are necessary to ensure that people with disabilities are afforded the same opportunity to participate in work and training activities

as other program participants. The federal TANF program gives states flexibility in establishing financial eligibility rules. Therefore, changes could be made at the state level to ensure that people with disabilities do not lose needed supports or training opportunities from TANF.

Exemptions on Food Stamps--An examination of the Food Stamp program is needed so that people who have earnings and savings do not lose needed food stamps.

Workforce Investment Boards--The One-Stop System services are not utilized to the fullest extent by individuals with disabilities in Virginia due to the lack of accessibility, few specialized staff/equipment and a poor understanding of people with disabilities and their specialized needs.

Other State Laws, Policies and Regulations:

- State Temporary Assistance Needy Families (TANF) Laws Code of Virginia §§ 63.2600 et seq.
- Virginia TANF Policy Manual – VIEW Program, Chapter 1000
- Exemptions on Food Stamps
- Department of Social Services Assisted Living Facility Auxiliary Grants
- Medicaid Buy-In Program development
- Home and Community Based Medicaid Waiver eligibility and income requirements
- Home and Community Based Medicaid Waiver earned income

Other Federal Laws, Policies and Regulations:

- Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (P.L. 104-193).
- The Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA)
- Health Insurance Portability and Accountability Act of 1996
- Section 8 Income Eligibility Requirements: Section 8 income eligibility needs to be made broader and more flexible so that people with disabilities who have earnings and savings do not lose their residence as a result of employment.

Other: Local community policies

Current programs and initiatives addressing the issue:

1. *Assisted Living Facility (ALF) Auxiliary Grant*, a grant administered by the Department of Social Services (DSS): Provided to eligible consumers, enabling them to reside in the community in ALFs. Serious financial disincentives exist for any employment or increased earnings by people with disabilities.
2. *Medicaid Home & Community Based Waiver Programs (HBC)* administered by the Department of Medical Assistance Services (DMAS): A wide array of services over and above State Plan Option for eligible consumers with disabilities. State earned income disregards exist in only three of six waivers in Virginia (MR, DD, and CD-PAS): a total of unearned and earned income of 200% of SSI for 8-19 hours worked per week; a total of unearned and earned income of 300% of SSI for 20 + hours per week.

3. *Olmstead WorkFORCE Coordinating Grant* administered by the Department of Rehabilitative Services (DRS): A Department of Labor, Office of Disability Policy, Grant to facilitate the integration of employment issues and planning into the states' Olmstead Planning Activities. In Virginia that includes the customization of WorkWORLD Decision Support Computer Software.
4. *Social Security Administration Benefits Planning Assistance and Outreach Program (BPAO)*, established by the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA) and administered by the Social Security Administration, VaACCSES, Blue Ridge Independent Living Center, Access Independence, Independence Center, and the Junction Center for Independent Living: This community-based program assists SSI and SSDI beneficiaries to understand the myriad of federal work incentives that are available in order for them to make an informed decision about work. SSA awarded five grants to community-based organizations in Virginia to provide all SSA disability beneficiaries (including transition to work aged youth) with free access to benefits planning and assistance services. The goal of the BPAO program in Virginia is to better enable SSA beneficiaries with disabilities (SSI and/or SSDI) to make informed choices about work by providing free, individualized information and referral, problem solving and advocacy, benefits analysis and advisement, benefits support planning and benefits management. Unfortunately, these five grantees are spread thin both financially and geographically to serve all of the SSA disability population.
5. *1619b Work Incentive Pilot Program (Part of the DMAS Medicaid Infrastructure Grant from CMS)*, administered by the Department of Medical Assistance Services (DMAS), Department of Social Services (DSS), Virginia Office for Protection and Advocacy (VOPA) and OneSource Grant Project of the Northern Virginia Workforce Investment Board: A pilot program established in Northern Virginia to educate all public and private disability service providers and other benefits professionals, as well as consumers and families, on the 1619b work incentive. The goal is to help people with disabilities gain employment and/or expand work hours, and gain eligibility to 1619b. A pilot in Northern Virginia was determined to be a logical geographic-demographic option due, in part, to the area's higher average income level and number of 1619b eligible individuals. Although 1619b has been a work incentive under SSI since 1987, people with disabilities in Virginia appeared to be incorrectly losing their Medicaid coverage when they should have retained coverage as a 1619b eligible. It was found that systems knowledge and education regarding 1619b has helped resolve this issue.
6. *Medicaid Buy-In program Development Medicaid Infrastructure Grant*, administered by the Department of Medical Assistance Services (DMAS) in collaboration with the Department of Rehabilitative Services (DRS), the Virginia Office for Protection and Advocacy (VOPA), Stakeholder Advisory Committees, and the Disability Commission: A four-year grant awarded in 2002 solicits input from consumers in the development of a Medicaid buy-In program to enhance employment options for people with disabilities.

7. *Ticket to Work and Self-Sufficiency Program of The Ticket to Work and Work Incentives Act of 1999 (TWWIA)*, administered by the Social Security Administration (MAXIMUS, Program Manager): The “Ticket to Work and Self-Sufficiency” program is the centerpiece of the TWWIA, and a key component of President Bush’s New Freedom Initiative. The goal of the “Ticket” program is to give disability beneficiaries the opportunity to achieve steady, long-term employment by providing them with greater choices and opportunities for obtaining employment, vocational and other support services from the public or private provider of their choice. The Social Security Administration began issuing tickets to first round states in February 2002, with the Virginia rollout in November 2002. The “Ticket” program is voluntary for both beneficiary and approved Employment Network providers (EN).

Disability populations impacted by the issue and how they are impacted: Consumers across disability lines are faced with losing services such as prescriptions, health insurance, housing, or other critical services because of increased income from employment.

Challenges:

1. Service infrastructure and design: There is no requirement that state agencies collaborate to advance employment for individuals with disabilities; no concerted effort to eliminate financial disincentives impacting individuals and their families; and no concerted effort to ensure that individuals with disabilities and their families are aware of work incentives and benefits.
2. Federal program issues.
3. Appropriate targeting of services.
4. Role of providers and provider availability.
5. Availability of community services and supports.
6. Service coordination among institutional and community providers.
7. Linkages with other services.
8. Monitoring and oversight.
9. Data/information system issues.

The Commonwealth must now take the time to examine and maximize the new federal employment advancement opportunities available to assist people with disabilities toward greater self-sufficiency. Concurrently, we must undertake system-wide policy review and coordination effort, as well as statewide system education, to ensure that financial disincentives are eliminated and pertinent public policies are updated and modified to work in harmony, allowing competitive employment career paths and the saving of resources for all Virginians equally.

D. REPORT OF THE HOUSING TEAM

- Team Chair:** Barbara Gilley (consumer), succeeding Bill Fuller
- Team Recorder:** Bill Ernst, Department of Housing and Community Development (DHCD)
- Agency Conveners:** Bill Ernst, Department of Housing and Community Development (DHCD)
Barry Merchant, Virginia Housing Development Authority (VHDA)

The Housing Team was representative of, and considered, the interests of all disability populations in its work.

Mission: The mission of the Housing Issues Team is to support the work of the Virginia Olmstead Task Force in developing an effectively working plan to ensure that Virginians with disabilities are able to exercise their rights, under all applicable federal, state and local laws, to housing in the most integrated setting that enables them to live as independently as possible according to their individual needs and preferences. Our focus is to identify barriers in the housing delivery system and develop workable options for overcoming those that interfere with an individual's ability to receive appropriate services and supports in the community.

Guiding Principles: To ensure maximum control over one's environment, housing choice, and support services, the full array of permanent and transitional housing options must be available. Permanent housing for people with disabilities must be:

1. Integrated within the community;
2. Affordable and accessible to:
 - Frail elders at risk of or already institutionalized who could live in the community with appropriate housing and supports;
 - Institutionalized individuals with disabilities, including people in state facilities, nursing homes, or other restrictive settings;
 - Individuals with disabilities at risk of institutionalization, including those in restrictive community settings, living at home with aging parents or other family members, or living elsewhere in the community, and on residential services waiting lists; and
 - Individuals with disabilities who are homeless as a result of being deinstitutionalized; and
3. Separate from supportive services and not made contingent on the receipt of services; however, supportive services must be:
 - Available and accessible if needed and desired; and
 - Flexible and individualized.

ISSUE: HOUSING BARRIERS

DESCRIPTION OF THE ISSUE: *What can the Commonwealth of Virginia do to assure that persons with disabilities can locate housing that is available, affordable, accessible, and appropriately situated with respect to the availability of supportive services? Individuals with disabilities who wish to exercise the same range of choice available to those without a disability face numerous barriers, including:*

- *Housing units lacking accessibility features for persons with mobility or sensory limitations;*
- *Housing costs significantly exceeding the resources of lower-income individuals;*
- *Limited availability even where units that are affordable, accessible or both actually exist; and*
- *Limited coordination with necessary supportive services—including cases where housing is contingent on and rigidly linked to supportive services or, conversely, where necessary services are unavailable or relatively inaccessible.*

Background and data: The premise inherent within the Olmstead decision that the unjustified isolation or segregation of individuals with disabilities must be ended by turning to community-based facilities will not be realized if appropriate housing opportunities are not available within the communities of the Commonwealth. This issue affects not only those who are currently institutionalized and ready to return to local settings, but also thousands of citizens with disabilities who regularly struggle with the need to find available housing that is affordable within their incomes, accommodates any mobility, sensory, or cognitive limitations, and is accessible to any necessary supportive services. In spite of federal and state programs that attempt to address the housing and service needs of people with physical and mental disabilities, these individuals continue to experience the most pressing unmet housing needs of any group qualifying for housing assistance. As documented in *Priced Out in 2000* and other sources using data from the HUD Worst Case Housing Report, the census, and the National Low Income Housing Coalition, the housing circumstances of persons with disabilities may have worsened, even during periods where housing conditions and affordability generally improved for other population segments.

Current programs and initiatives addressing the issue:

1. *Tenant-based Section 8 housing voucher programs:* HUD's housing voucher programs provide rent subsidy payments to help low-income households pay the difference between the amount of rent they can afford and the full market rent for a qualifying housing unit that the household selects on the open market. (The landlord must be willing to accept the voucher.) All funding is competitive. "Fair Share" funds are allocated to states, and then distributed competitively to eligible public housing agencies. HUD distributes "Mainstream" vouchers, which exclusively target people with disabilities, through a national lottery. Local public housing agencies (PHAs) can apply to HUD for allocations of funds that provide vouchers to qualified renters. VHDA acts as a PHA on behalf of localities that do not have a HUD-approved local

PHA. Nonprofit organizations, as well as PHAs, can administer “Mainstream” vouchers.

2. *Project-based Section 8 programs:* HUD’s “project-based” Section 8 programs provide rent subsidy payments to low-income households residing in specific rental housing properties developed with HUD financial assistance. Local public housing agencies (PHAs) can set aside up to 15% of their voucher funds (see # 1 above) to use as “project-based” assistance. Private landlords administer the subsidy for all or a portion of the units in their housing development. (There are separate waiting lists for each participating rental property.) Private developers are eligible to apply to PHAs for project-based voucher funds. (Not all PHAs choose to create project-based voucher set-asides.)
3. *Section 202 and Section 811 programs:* HUD’s Section 202 and Section 811 programs provide capital grants and project operating subsidies for development that address the housing and support service needs of low-income elderly and disabled households. Private nonprofit organizations are eligible to apply annually to HUD on a competitive basis for development funds and operating subsidies.
4. *Section 515 program/Rental Assistance program:* The Rural Housing Service of the U.S. Department of Agriculture provides low-interest financing and “project-based” rent subsidy funds for housing developments in rural areas that serve low-income households. (Currently, new funding is available mainly to preserve existing Section 515 developments.) Private developers are eligible to apply to annually to RHS on a competitive basis for Section 515 loans and for rent subsidies for all or a portion of the units in their housing development. (There are separate waiting lists for each participating rental property.)
5. *Public Housing:* HUD provides annual subsidies to local public housing authorities to support the ongoing operation of publicly owned and managed housing units serving low-income households. Five percent of public housing units are required to be accessible, and an additional two percent of units are required to provide specific accommodations for people with vision or hearing impairments. Most Public Housing is 30+ years old, and many projects are being phased out through the HUD HOPE VI program or other redevelopment efforts. Replacement units for demolished Public Housing are being provided through other programs described in this section. Local public housing authorities administer Public Housing pursuant to HUD regulation and oversight.
6. *HOME block grant program:* HUD provides HOME funds to certain urban localities and states. HOME funds can be used for a wide array of purposes (for example, development, technical assistance and capacity building, and rent/operating subsidies). Program administrators must set aside a share of funds for community-based housing development organizations (CHDOs). CHDO funds are used for technical assistance and capacity building as well as for direct funding of local CHDO housing activities. HOME funds are distributed annually eligible localities and states according to a national formula. HOME funds are administered by large “entitlement” cities and urban counties, consortia of adjacent localities, and states.

States can use HOME funds in any locality. Both states and localities allocate funds to CHDOs to carry out housing programs.

7. *Community Development Block Grant (CDBG) program*: HUD provides CDBG funds to certain larger urban localities and to states. CDBG funds are used for community and economic development programs as well as for housing, and fund primarily development costs. CDBG funds are distributed annually to eligible localities and states according to a national formula. Large “entitlement” cities and urban counties, and states administer CDBG funds. States can use CDBG funds only in non-entitlement localities.
8. *McKinney Act homeless assistance programs*: HUD provides federal McKinney Act funds for a variety of homeless assistance housing and services programs, including monies for emergency shelter, transitional housing and permanent supportive housing. Annual allocations of funds are administered by states. Other funds are provided competitively to local project and program sponsors through local “continuum of care” consortia.
9. *Low-Income Housing Tax Credits*: The federal Low-Income Housing Tax Credit program provides tax benefits to developers of rental properties serving households with income less than 60% of the area median. Most developers sell the tax credits to investors in order to raise equity funds and reduce borrowing costs, thereby enabling affordable rents. Rental properties financed with tax-exempt bonds automatically qualify for tax credits. Developers of rental properties financed from other sources must compete for credits from a pool allocated annually by the IRS to the state. VHDA competitively allocates tax credits on behalf of the state to qualifying rental developments, and administers “automatic” tax credits to properties financed with tax-exempt bonds.
10. *Tax-exempt mortgage revenue bond programs*: Tax-exempt bonds are sold subject to federal regulations and restrictions to fund mortgage loans at below-market interest for affordable rental housing developments. The properties financed with bonds automatically qualify for federal Low-Income Tax Credits (see # 9 above). VHDA is the primary issuer of tax-exempt mortgage revenue bonds in Virginia. VHDA provides tax-exempt bond financing to qualifying rental developments on an ongoing first-come, first-served basis. Local housing authorities also issue tax-exempt bonds to finance rental housing.
11. *Taxable bond financing programs*: VHDA issues taxable bonds to finance affordable rental housing. VHDA blends taxable and tax-exempt bonds to increase the amount of available tax-credits. (Developments that are financed with at least 50% tax-exempt funds still qualify for “automatic” Low-Income Housing Tax Credits.) VHDA also uses taxable bonds to fund developments that are using competitive Low-Income Housing Tax Credits (see # 9 above). VHDA provides taxable bond financing to qualifying rental development on an ongoing first-come, first-served basis.
12. *Virginia Housing Fund (VHF)*: The Virginia Housing Fund is a loan pool capitalized by VHDA’s General Fund balance that is used to provide low-interest financing under flexible terms and conditions for a wide array of housing serving low-income

populations. VHF funds can be used to finance independent apartments as well as single room occupancy developments (SROs), group homes, transitional housing, and other types of supportive housing serving people with disabilities. VHDA provides VHF loans on a first-come, first-served basis to public and private sponsors of housing serving low-income households.

13. *Virginia Housing Partnership Fund (VHPF)*: The Virginia Housing Partnership Fund was established by the state as a revolving loan fund to provide low-interest and no-interest first mortgage and gap financing for housing serving low-income households. Under the FY 2004 budget adopted by the 2003 General Assembly, VHDA is to purchase the assets of the VHPF in order to provide \$41 million to help close the state's budget gap. An as yet undetermined amount is expected to remain after payment to the state for use in operating housing programs serving the same purpose as the original VHPF. Beginning in FY 2004, VHDA will own the assets of the VHPF rather than the state. However, the administration of VHPF programs will continue as in the past—i.e., DHCD will establish programs and review and approve applications for funding, with VHDA providing underwriting, loan servicing and management of funds.
14. *Home improvement loan programs*: HUD insures home improvement loans made by public and private lenders through the Title I program. These loans are made under more favorable terms and conditions than are generally available through conventional private lending programs. VHDA provides Title I loans at a below-market interest rate. Title I loans can be used to fund accessibility accommodations to single family homes. HUD Title I loans are made through VHDA as well as through private lenders.
15. *Home Equity Conversion Mortgage (HECM) program*: HUD insures “reverse mortgage” loans through the HECM program. HECM loans enable low-income homeowners age 62 and older to access their home equity without having to make repayment until they die, move, or sell their home. HECM loans can be structured as a line of credit and used by seniors with disabilities to fund in-home services and/or accessibility accommodations. Free counseling is mandated for all HECM borrowers to ensure that they understand their financial options and are comfortable that a reverse mortgage is the most appropriate way to meet their needs. HECM loans are originated through private lending institutions. HUD-approved nonprofit housing counseling agencies provide counseling to eligible individuals.
16. *Home accessibility retrofit tax credit program*: The Virginia tax code permits a limited tax credit to individuals who retrofit an existing residence with one or more specified accessibility features. These features include: (i) one no-step entrance allowing access into the residence; (ii) interior passage doors providing a 32-inch wide clear opening; (iii) reinforcements in bathroom walls and installation of grab bars; (iv) light switches and outlets placed in wheelchair-accessible locations; and (v) universal design features or those accessibility or adaptability features prescribed in the Uniform Statewide Building Code (USBC). Individual taxpayers apply to the Department of Taxation for the credit, which is limited to an aggregate of \$1 million for any taxable year.

17. *Rent reduction tax credit program:* This program provides a tax credit to qualifying individuals and corporations that provide rent reductions of at least 15 percent to elderly, disabled or previously homeless tenants, for taxable years through December 31, 2005. The tax credit is 50 percent of the total rent reductions allowed, not to exceed the taxpayer's tax liability, and is applicable only to units upon receiving credits for all or part of the month of December 1999. VHDA certifies to the Department of Taxation the eligibility of the individual or business claiming the credit, which is limited to an aggregate of \$50,000 for any fiscal year.
18. *State and local Mental Health, Mental Retardation, and Substance Abuse Service (DMHMRSAS) funds:* DMHMRSAS allocates state general funds to Community Services Boards (CSBs), which also provide local match and other funds to meet the housing and residential service needs of Virginians with mental health, mental retardation and substance abuse disabilities. The array of housing supports provided through this state and local partnership includes supervised group homes and apartments, off-site staffing for services and supports to individuals in regular housing, development and management of affordable housing units, and the provision of rental assistance and other housing subsidies. DMHMRSAS provides state general funds to CSBs, which provide a local match. CSBs have wide latitude in the types of housing services they administer to individuals with mental illness, mental retardation and substance abuse disorders using these state funds, their local match, and other funding resources.
19. *Assistive Technology Loan Fund (ATLFA):* The Assistive Technology Loan Fund Authority provides guarantees for bank loans, or direct loans for the acquisition of equipment needed to increase the independence of persons with disabilities. Loans may be used for home modifications such as ramps, stair climbers, and bathroom modifications. Home equity loans may be used for more extensive home renovations, including additions needed to enhance independence. SunTrust Bank, which is ATLFA's contractual partner, provides loan origination services to borrowers through its consumer home equity lending department.

An appendix at the end of the Housing Team report presents a table summarizing various housing options available for persons with disabilities.

Disability populations impacted by the issue and how they are impacted: This issue impacts all populations.

Challenges:

1. Service infrastructure and design:
 - Local infrastructure is inadequate to support community-based housing opportunities. There is a poorly developed local infrastructure for developing and managing housing designed to meet the special needs of people with disabilities. To the extent that local infrastructure exists, it varies considerably in nature and capacity across regions of Virginia, and often, even within regions. The primary reason for insufficient infrastructure is that most federal and state housing programs rely on private sector entities to deliver housing assistance at the local level through the marketplace.

Traditional for-profit housing development entities (and also many nonprofits) lack incentives to provide specialized services to people with disabilities. The size of the local market with income sufficient to pay for unsubsidized housing and services is too small to support interest on the part of most private-sector housing interests. A significant share of potential housing demand can become effective only if deep housing and service subsidies are provided. The primary current sources of new deep subsidy funds are the Housing Choice Voucher and Medicaid waiver programs. Those programs presents two nearly insurmountable barriers to private developers: 1) the programs are not entitlements—there are long waiting lists for both types of assistance; and 2) the programs are “consumer-based,” so that developers are uncertain of their ability to attract sufficient numbers of people holding vouchers and/or Medicaid waiver slots to maintain the feasibility of their developments. Effectively bringing together housing development resources and consumer-based housing and service subsidies requires strong local partnerships through which resource coordination can occur. Most local private housing development entities lack the resources and/or motivation to pull together such partnerships on their own. Therefore, they turn their energies to other needs that they can more readily address.

- There are cost inefficiencies in the delivery of residential services in supportive housing developments. HUD maintains tight cost controls on operating budgets for Section 811 supportive housing developments. The small size of Section 811 developments (limited to 14 residents) makes it extremely difficult to deliver needed residential services on a cost-effective basis unless residents can pool hours for caregiver services. However, DMAS regulations bar this practice.
- The current Assisted Living Facility (ALF) system does not adequately address the need for quality supportive housing for lower income persons. State and local governments continue to provide considerable funding to support the operations of ALFs throughout Virginia through the Auxiliary Grant program. However, that program was designed to fit a now antiquated model of board and care, and continues to operate under reimbursement levels that are insufficient to provide quality care. Therefore, most ALFs providing quality care do so on a private pay basis and are unaffordable to lower income persons. Furthermore, some people with disabilities who are dependent on SSI and need ALF services are effectively limited to residing in ALFs in order to receive subsidized shelter and care. While ALFs are an important and necessary component of the of the universe of housing options required to meet the needs of persons with disabilities for housing with appropriate levels of supportive services, a broader range of options is needed to address consumer needs and preferences, and to ensure adequate quality. Sole reliance on the current Auxiliary Grant program as a subsidy source inhibits efforts to improve the quality of ALFs or develop appropriate alternative options.

2. Federal program issues:

- There are substantial barriers to maximal use of federal Housing Choice Vouchers. Landlords are not required to participate in the voucher program. In strong rental housing markets, there is little incentive for landlords to participate. Landlord participation is further discouraged by community “not in my back yard” (NIMBY) attitudes toward low-income and special need housing. In addition, tight rental market conditions in many metropolitan areas are pushing market rents above HUD’s

payment standard for the voucher program. Consequently, there is a shortage of rental units available to voucher holders, especially outside the areas of low-income and minority concentration. The shortage of available rental units is resulting in substantial numbers of “unused” vouchers (i.e., vouchers assigned to eligible households but not yet in use), despite long waiting lists for assistance. HUD is under Congressional pressure to aggressively recapture such “unexpended” voucher funds. People with disabilities face even greater problems in using vouchers. There is a shortage of accessible units available to voucher holders. The Fair Housing Act requires landlords to make reasonable physical accommodations, but it is the tenant’s responsibility to pay for such modifications. Voucher holders generally lack access to resources to pay for needed modifications. This leads to even longer housing search periods than for other voucher holders. Public housing agencies can grant time extensions to people with disabilities as a reasonable accommodation. However, doing so increases their number of un-leased units and the risk of funds recapture by HUD. Many PHAs are struggling to keep their programs fully leased. This discourages applications for additional vouchers, especially Mainstream vouchers that require more work than regular vouchers (i.e., coordination with local human service agencies to facilitate supportive services) and for which the odds of receiving funds are low under the current national lottery system.

- Existing federal deep “project-based” subsidies are at risk, and new project-based rent subsidies are scarce and difficult to access and use. A large portion of the rental units affordable to low-income households is privately owned rental housing with assigned federal “project-based” rental subsidies. This private housing was mainly developed from the late 1960’s through the middle 1980’s, and many of its owners are now eligible to prepay their mortgages and/or opt-out of their federal rent subsidy contracts. Removal of subsidies from this housing over the past decade has been a major contributor to the severe shortage of housing affordable to low-income households. The federal government has largely eliminated new project-based rent subsidy funds in favor of tenant-based voucher assistance. Nonetheless, many types of supportive housing serving extremely low-income people with disabilities require project-based rental assistance and/or equivalent operating subsidies in order to be feasible. Such subsidies are now extremely scarce and difficult to access. In addition, the federal government has imposed progressively more stringent cost controls, so that gap financing is now needed to make development of housing using project-based subsidies feasible.
- There are a number of significant barriers to using Medicaid funds to address service costs in supportive housing and costs associated with the transition to community living. Supportive housing developments are difficult to structure using Medicaid funding to subsidize residential service costs because of DMAS regulations impeding the use of pooled caregiver hours and inadequate reimbursement rates. Current DMAS reimbursement rates for support services do not reflect the real cost of providing quality services and discourage providers from serving Medicaid recipients. More funded waiver slots are needed to restore equity and reduce substantial waiting lists. In addition, regulations make it difficult to use Medicaid funds to cover many of the necessary costs associated with transitioning from an institutional residence to community housing. For example, individuals needing environmental modifications

to community housing cannot access funding for these services prior to discharge from an institutional setting. Institutionalized persons are also unable to save money for expenses such as first month's rent and utility deposits, and essential furniture and household items. Virginia's use of the Medicaid program to fund community-based services for persons with disabilities has been problematic in several respects. Virginia is not taking full advantage of the matching federal funds available through Medicaid, forgoing the opportunity to maximize its use of state and local dollars spent on residential support services. At the same time, an increasing reliance on Medicaid as a primary funding source, without providing adequate state matching funds, increasingly limits the availability of services for other non-eligible consumers. Finally, the state's Medicaid plan lacks the flexibility required to meet the variety of individualized service needs relevant to successful community living for persons with disabilities.

- Financial thresholds that determine eligibility for services, benefits, and resources for individuals with disabilities create disincentives for individuals to participate in gainful employment because of the limits they may place on that individual's access to or maintenance of benefits or other resources that support an individual's ability to live and work in the community. In areas ranging from housing to health insurance coverage to personal care, substantial financial disincentives, actual or perceived, impede individuals with disabilities who seek self-sufficiency through competitive employment. Often these disincentives cause individuals to lose the services and supports they require to maintain employment and economic independence. Dated, complex and conflicting federal, state, and local disability policies' financial disincentives also hamper family members and service providers. To assist individuals with disabilities in participating fully in communities across the Commonwealth, greater public awareness about disability policies, across agencies and programs, with an emphasis on advancing economic empowerment through employment, is imperative. In Virginia, as in other states, many individuals with disabilities have learned that attempts to increase self-sufficiency may lead to serious personal and financial loss of critical benefits and other resources. In many instances, individuals experience the loss of the basic benefits needed to live in the community. These include, but are not limited to, services and supports related to health care, personal assistance services (PAS), housing, transportation, mental health care, and medical management. Individuals may lose a Medicaid waiver—and the healthcare and support services it covers, food stamps, and other services and benefits driven by financial eligibility criteria. Social Security benefits overpayment and required repayment are also problematic. Experientially, individuals with disabilities and their service providers know that an increase in an individual's earned income can terminate critical family services and supports, including funding streams accessed through federal, state, and local governments. It is often with great trepidation that individuals with disabilities and their providers would now consider full time competitive employment as a goal.
3. Appropriate targeting of services: Lack of full understanding of the substantial differences in local needs, priorities and strategies often inhibits the effectiveness of state-level planning and program implementation. Past joint program efforts between VHDA and DMHMRSAS, and VHDA and the Department of Aging have achieved

uneven success across the state because of differing local needs and the priorities and strategies of local Community Service Boards (CSB) and Area Agencies on Aging (AAA) that were not fully reflected or addressed in state-level program planning and implementation.

4. Role of providers and provider availability:

- Insufficient landlord participation in the Housing Choice Voucher program is a major barrier to full and effective use of this subsidy resource. (See discussion of this challenge under Federal program issues, # 2 above.)
- Inadequate local infrastructure to support community-based housing opportunities is a major barrier to housing providers serving disability housing needs. (See discussion of this challenge under Service infrastructure and design, #1 above.)
- Medicaid rates for community-based support services are insufficient to enable Medicaid use by supportive housing providers. (See discussion of this challenge under Federal program issues. # 2 above)

5. Availability of community services and supports:

- Obstacles to full utilization of Housing Choice Vouchers are a major barrier to the availability of community services and supports. (See discussion of this challenge under Federal program issues, # 2 above.)
- Inadequate local infrastructure to support community-based housing opportunities is a major barrier to the availability of community services and supports. (See discussion of this challenge under Service infrastructure and design, # 1 above.)
- There is a severe shortage of available housing meeting the accessibility needs of people with disabilities. Only a very small share of existing housing units are accessible, and most people with disabilities lack sufficient resources to make needed modifications without some form of financial assistance. There are few incentives for homeowners or landlords to make accessibility modifications to their housing since such improvements can rarely be recouped through increased property value. In addition, people with disabilities lack information on how to locate the existing accessible housing as well as available resources to assist them in making necessary accessibility accommodations.

6. Service coordination among institutional and community providers: The Medicaid program imposes significant barriers to smooth transition from institutional residence to community housing. (See discussion of this challenge under Federal program issues, # 2 above.)

7. Monitoring and oversight: Understanding and enforcement of state and federal accessibility requirements need to be strengthened. Recent compliance studies suggest that the accessibility requirements contained in the Uniform Statewide Building Code, the Fair Housing Act, the Americans with Disabilities Act, and Section 504 of the Rehabilitation Act of 1973 are neither fully understood by building professionals and rental housing owners nor being consistently enforced.

8. State and local regulations:

- Current building code accessibility requirements are creating insufficient numbers of accessible housing units. Broader building code accessibility requirements are needed to create sufficient numbers of accessible housing units to provide adequate

ongoing market availability. Expanding accessibility requirements to include single-family, owner-occupied dwellings would facilitate the ability of people who acquire disabilities to remain in their homes and provide for “visability” by friends and family members with disabilities. This would increase the stock of at least minimally accessible units.

- Localities are increasingly imposing land use regulations and practices that negatively influence the provision of affordable, accessible housing.
 - Fiscal stresses on local governments and the present high demand for “trade up” homes are causing increasing numbers of localities to impose regulations and practices that restrict the amount of land available for higher density, affordable housing. Frequently, supportive housing cannot be developed without a special use permit, which enables needed housing to be blocked by local “not in my back yard” (NIMBY) attitudes.
9. Legislative requirements:
- People with disabilities are being discriminated against based on source of income. Some landlords are imposing minimum income requirements that do not consider public benefits such as SSI or the value of a Housing Choice Voucher as income. This practice prevents occupancy by many people with disabilities.
 - People with disabilities do not receive timely information about the availability of accessible housing units. Providing people with disabilities with advanced notice of the availability of accessible housing can help assure that an already scarce housing resource will be used more effectively to meet needs the needs of persons with mobility, sensory, or other limitations that could benefit from housing with appropriate accessibility features.
10. Allocation of state and local housing subsidies and resources: People with disabilities need increased access to limited housing subsidies. A majority of people with severe disabilities has limited employment income and requires deep housing subsidies in order to obtain adequate housing. Such subsidies are extremely limited relative to need. Therefore, sufficient housing resources cannot be made available to address the needs of Olmstead populations unless their needs are prioritized by state and local housing agencies.
11. Education and training: Lack of knowledge and understanding of Universal Design is inhibiting the creation of a more accessible housing stock. The current housing stock is not well suited to the needs of an aging population with a growing share of people with disabilities. In order for substantial changes to occur, knowledge and understanding of Universal Design must be increased among housing and building professionals, and political decision makers.

Recommendations:

- HI.1.a. Build adequate local infrastructure to support community-based housing opportunities. VHDA and DHCD should team with DMHMRSAS and DRS to meet with local CSBs, CILs and DSBs in order to: 1) provide training on best practices in building and sustaining local affordable and

accessible housing partnerships; and 2) determine on a regional basis the local capacity for delivering affordable and accessible housing.

- HI.1.b. Facilitate cost-efficient delivery of residential services in supportive housing developments. DMAS should make changes in Virginia's Medicaid waiver programs as needed to allow the pooling of care provider hours in supportive housing developments.
- HI.1.c. Establish alternative funding mechanisms to the current Auxiliary Grant program for subsidizing assisted living services. The General Assembly should direct DSS, DMHMRSAS, and other potentially affected agencies and organizations to examine the establishment of alternatives to the current Auxiliary Grant program. A new approach to assisting low-income people being served by ALFs as well as in alternative settings could provide both a higher level of reimbursement and higher expectations for the quality of residential services being provided.
- HI.2.a. Maximize the use of federal Housing Choice Vouchers. VHDA should work with VAHCDO to develop state and local consensus on, and advocate at the federal level for, strategies to: 1) maximize the number of available vouchers for persons with disabilities; 2) increase landlord participation in the voucher program, especially outside areas of low-income and minority concentration; and 3) provide resources to fund physical accommodations required by voucher holders with disabilities.
- HI.2.b. Maximize the use of federal deep "project-based" housing subsidies. VHDA and DHCD should work with VAHCDO to develop consensus on joint state and local strategies to: 1) preserve existing federal deep subsidy rental units; 2) provide necessary gap financing for new HUD Section 811 and RHS Section 515/rental assistance (RA) developments; 3) use project-based vouchers to increase the supply of affordable, fully accessible units; and 4) mandate the allocation of accessible Section 8 units to people with disabilities. A thorough review of the marketing of accessible Section 8 units is necessary to determine how to make the requirements of Section 504 more effective.
- HI.2.c. Facilitate delivery of residential services in supportive housing developments. DMAS should make changes in Virginia's Medicaid waiver programs as needed to allow greater use of pooled hours and shared care providers, while insuring consumer choice in supportive housing developments.
- HI.2.d. Use Medicaid program requirements to facilitate a seamless transition to community living. Modify Virginia Medicaid program rules to provide a seamless transition from an institution to the community.
- HI.2.e. Increase Medicaid funding for community-based support services by increasing: 1) DMAS reimbursement rates for case management and other services; and 2) the availability of funded Medicaid waiver slots, including cash and counseling and other options, to meet growing needs.

- HI.3. Increase state-level understanding of local and regional needs and priorities. VHDA and DHCD should team with DMHMRSAS and DRS to meet with local CSBs, CILs and DSBs to better understand differences in local and regional needs and strategies, and to determine the local/regional prioritization of gaps needing to be addressed with state resources.
- HI.4.a. VHDA should work with VAHCDO to develop state and local consensus on strategies to increase landlord participation in the voucher program, especially outside areas of low-income and minority concentration.
- HI.4.b. Build adequate local infrastructure to support community-based housing opportunities. VHDA and DHCD should team with DMHMRSAS and DRS to meet with local CSBs, CILs and DSBs in order to: 1) provide training on best practices in building and sustaining local affordable and accessible housing partnerships; and 2) determine on a regional basis the local capacity for delivering affordable and accessible housing.
- HI.4.c. Increase Medicaid rates for community-based support services. In determining appropriate rates, transportation costs should be considered.
- HI.5.a. Maximize the use of federal Housing Choice Vouchers. VHDA and DHCD should work with VAHCDO to develop state and local consensus on strategies to provide resources to fund physical accommodations required by voucher holders with disabilities.
- HI.5.b. Increase state-level understanding of local and regional needs and priorities. VHDA and DHCD should team with DMHMRSAS and DRS to meet with local CSBs, CILs and DSBs in order to better understand differences in local and regional needs and strategies, and to determine the local and regional prioritization of gaps needing to be addressed with state resources.
- HI.5.c. Modify the existing housing stock to meet accessibility needs. Establish a home accessibility modification grant program for individuals who cannot access other funding sources for essential accessibility modifications, and expand and make permanent state tax incentives for private homeowners and landlords who upgrade their housing to a defined level of accessibility.
- HI.5.d. Assist people with disabilities in accessing housing suitably adapted to their individual needs by establishing information services to connect people seeking accessible housing with available accessible units and home modification resources.
- HI.6. Use Medicaid waivers to facilitate a seamless transition to community living by modifying Virginia Medicaid waiver rules to provide a seamless transition from an institution to the community, and to provide one-time start-up funding to persons transitioning to the community.
- HI.7.a. Increase effective enforcement of existing state building regulations. The Board of Housing and Community Development should ensure that local

building code officials are adequately trained to ensure full compliance with the accessibility requirements of the Uniform Statewide Building Code.

- HI.7.b. Increase understanding and enforcement of the accessibility requirements of the Fair Housing Act, the Americans with Disabilities Act (ADA), and Section 504 of the Rehabilitation Act of 1973. Virginia's Fair Housing Office should expand efforts to educate building industry professionals and rental property owners of their responsibilities under the Fair Housing Act, the ADA, and Section 504 of the Rehabilitation Act of 1973, take stronger enforcement actions to ensure compliance with the Fair Housing Act, and coordinate with appropriate federal enforcement officials to increase compliance with ADA and Section 504 requirements.
- HI.8.a. Expand accessibility requirements under the Uniform Statewide Building Code (USBC). The Board of Housing and Community Development should consider broader housing accessibility requirements in the USBC. In promulgating the USBC, the Board should assure as a minimum that the code provisions fully incorporate the 1988 Fair Housing amendments. In addition, the Board should consider expanding accessibility requirements to all housing governed by the code. These "visitability" standards should include: 1) one zero step entrance; 2) an accessible path to the entrance; 3) 32-inch-wide doors throughout the ground floor; 4) accessible environmental controls; 5) one usable bathroom on the ground floor; and 6) reinforcements behind bathroom walls.
- HI.8.b. Eliminate local regulatory barriers to affordable, accessible housing. DHCD and VHDA should work with disability groups and housing industry associations to educate local governments, the General Assembly and the public on the negative impact of many local land use regulations and practices on the creation of affordable and accessible housing. In addition, the General Assembly should follow up recent requirements mandating that local plans specifically address affordable housing needs with a similar requirement addressing the need for affordable and accessible housing.
- HI.9.a. Eliminate barriers to landlord discrimination against Section 8 voucher holders and other benefit recipients. The General Assembly should consider legislation that would require landlords to treat as income the value of a Housing Choice Voucher or other public benefits for individuals with disabilities.
- HI.9.b. Provide a notification system working with disability advocacy organizations so that persons with disabilities receive advanced notice of the availability of accessible housing units. The General Assembly should consider legislation requiring that owners and managers of fully accessible housing post advance notice of the availability of accessible housing units with local or regional disability housing advocacy organizations before making such units available on the open market.

HI.10. State and local agencies should prioritize the needs of people with disabilities in the allocation of housing subsidies and technical assistance resources. The General Assembly should direct VHDA and DHCD to give priority to the housing needs of people with disabilities in allocating Section 8 voucher assistance, grant funds, low-interest and no-interest loan funds, and technical assistance resources. In addition, the General Assembly should require local governments and PHAs to prioritize the housing needs of people with disabilities in allocating locally-administered housing subsidies and resources.

HI.11. Provide ongoing training in Universal Design. State universities and community colleges should be charged with providing ongoing training in Universal Design to architects, building officials, elected officials, housing providers, funding agencies, licensing staff, and community-based organizations to ensure consideration of aging-in-place issues in the development of community housing options.

Housing Type	Licensed	Required service participation	Occupancy restricted by disability
Fully Private Permanent Housing (no shared living facilities)			
Owner-occupied and rental housing —Includes single-family detached homes, townhouses, manufactured housing, and apartments (including single-room occupancy with private kitchenette/bath facilities)	No	Sometimes in rental housing	Sometimes in rental housing
Permanent Rental Housing with Shared Living Facilities			
Shared Housing —Housing shared by two or more unrelated individuals under a single lease agreement. This can occur in any type of rental housing.	No	Sometimes	Sometimes
Single Room Occupancy (SRO) —Minimal size single room housing units with shared bath and/or kitchen/dining facilities. Typically found in residence hotels, boarding houses and similar accommodations.	No	Sometimes	Sometimes
Congregate Housing —Housing that provides private living space (with or without a kitchenette) with a shared central kitchen and dining room that provides at least one meal a day to residents. Other non-medical/personal care services may be provided as well including transportation, linens, housekeeping, etc.	No	At least one meal a day is required	Sometimes
Assisted Living —Housing that provides three meals a day along with licensed supportive/personal care services to residents as a condition of occupancy. Facilities are licensed to provide specific levels of supportive/personal care services. Assisted living may be provided in a variety of large and small settings including apartment buildings, rooming houses and group homes. Living accommodations can include:	Yes	Yes	Yes

Housing Type	Licensed	Required service participation	Occupancy restricted by disability
<ul style="list-style-type: none"> • Private apartment (with or without a kitchenette) • Private room and bath (with shared living room) • Private room (with shared bath and living room) • Shared room (with or without a private bath and with a shared living room) 			
Nursing Home —Housing providing licensed nursing care services. Facilities may provide either private or shared rooms and baths.	Yes	Yes	Yes
Temporary Housing			
Emergency Housing —Temporary housing provided to homeless people and people in crisis. Housing may be of a variety of types (including shelters) and may include private or shared accommodations.	No	Sometimes	Sometimes
Transitional Housing —Housing provided to people transitioning to community living for a specified period (generally six months to several years) while they are gaining independence. Housing may be of a variety of types and may include private or shared accommodations.	No	Yes	Sometimes
Residential Treatment Programs —Housing and recovery treatment services provided on a generally short-term basis to people recovering from substance abuse. Housing may be of a variety of types and may include private or shared accommodations.	Yes	Yes	Yes

E. REPORT OF THE PREVENTION AND TRANSITION SERVICES TEAM

Team Chair: Ian Kremer, Alzheimer’s Association of Virginia

Team Recorder: Teja Stokes, ARC of Virginia

Agency Convener: Jerry Deans, Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS)

The Prevention and Transition Issues Team invited all disability populations to participate in and/or be represented on the Team.

Vision and values:

The Prevention and Transition Issues Team’s overarching values are:

- Building capacity: a forward thinking perspective on what future needs may be and what the present unmet need is;

- Consumer-driven, consumer-directed services and choice;
- Cultural competency and diversity;
- Public/private partnerships;
- Service delivery need, not label;
- Speaking as one voice, benefiting all; and
- Money follows the person, and the pie must expand.

ISSUE I: PLANNING PHILOSOPHY

DESCRIPTION OF THE ISSUE: *Planning philosophy is viewed as a critical element for attention in the development of and ongoing evaluation of Virginia's Olmstead Plan. Some important elements of this issue include the following:*

- *There is inconsistent sharing of information and lack of meaningful participation in the planning process by those affected. This should occur during both the planning and implementation phases, include all stakeholders, both public and private, and be accomplished regionally, if and when appropriate.*
- *Planning too often does not include a focus on replicating best practices and mirroring model community programs from Virginia as well as from other states. This should be incorporated into planning of treatment at the micro and macro levels, along with full acceptance of the models of recovery and psychosocial rehabilitation, where applicable.*
- *Services are not uniformly accessible in all localities across the state. A consistent minimum level of service should be achieved through the provision of appropriate administrative, fiscal, and technical support during the implementation, evaluation, and revision of community programs.*
- *Consumer and family experiences are not integrated into planning and service delivery. This should be addressed throughout the system, with eventual movement toward provision of more services by consumers.*
- *Access to short-term institutionalization often results in loss of funding or slots upon return to the community (as well as the converse). Safeguarding funding and slots during institutionalization would expand the continuum of care significantly.*
- *Payment is targeted to programs and services rather than to achieving positive outcomes. This reduces the focus on, and awareness of, treatment effectiveness.*
- *Funding policies inhibit, rather than support, ease of movement along the continuum of care, and thus hinder rehabilitation and recovery. Coordination of funding and policy objectives among state agencies should be a goal, with particular focus on early intervention.*
- *Current planning is not mindful of the projected change in demographics for Virginia over the next decade. Based on these changes, particular sensitivity should be maintained to insure that cultural and language needs of consumers and families are congruent with the assigned workforce.*
- *Service planning relies upon historical or existing data. It should be based on data that provides future projections of population prevalence and incidence, workforce attributes and so forth.*

- *The needs of children and adolescents are overlooked. Higher priority should be given to development and evaluation of a comprehensive system of care to meet the needs of the child and adolescent population.*

Background and data: A shift in the philosophy of planning community-based care to be more inclusive, collaborative, outcome oriented, and aiming for the maximum empowerment and self-determination of consumers and/or consumers' responsible representatives will positively influence other aspects of treatment delivery toward maximizing quality and effectiveness of care, as well as consumer satisfaction with the service delivery system.

Relationship between the issue and current laws, regulations and policies: State policies and regulations should be amended to improve interagency collaboration at all levels, as well as to increase meaningful inclusiveness by all stakeholders during the planning phase. Where existing collaborative activity is regulated, enforcement of accountability should occur.

Current programs and initiatives addressing the issue:

1. *Shelter Plus Care*, a model program for persons who are homeless, is currently in place in Roanoke, Virginia and other localities.
2. *Wraparound Milwaukee*, a program for adolescents with serious emotional disturbance, is administered by the State of Wisconsin.

Disability populations impacted by the issue and how they are impacted: This issue impacts all populations.

Challenges:

1. Service infrastructure and design: Collaboration and inclusiveness in design and planning of community treatment is not emphasized.
2. Appropriate targeting of services: Needs assessment, outcome data, and best practices research data is difficult to obtain and little used.
3. Role of providers and provider availability: See above.
4. Availability of community services and supports: See above.
5. Service coordination among institutional and community providers: Many important service coordination linkages are weak.
6. Linkages with other service systems: Weak linkages across systems impair interagency collaboration, and enforcement and accountability at all levels of administration is limited.
7. Monitoring and oversight: Monitoring and oversight of collaboration and inclusiveness is limited.
8. Data/information system issues: Data on collaboration and inclusiveness is lacking.
9. Exclusion of stakeholders: Relevant stakeholders are often excluded from membership on planning and decision-making groups.

ISSUE II: LACK OF COMMUNITY-BASED SERVICES

DESCRIPTION OF THE ISSUE: *Community-based services are essential to prevent unnecessary or premature institutionalization and to transition from institutional care to integrated community settings. For all disability populations, there are too few appropriate community-based services and supports. Examples identified by the team include short-term and long-term residential services; respite for caregivers; in-home treatment, health, personal assistance and education services and supports; day treatment, rehabilitation and adult day care services; education, training and employment and other services that develop or strengthen independent living skills and support independent living; tele-medicine and related tele-therapies; suicide prevention programs; and training and support to providers. (See “Additional Information” below for a complete list of issues identified by the team).*

In addition, effective discharge planning is confounded by the lack of community-based services and funding. Services identified in discharge plans of persons transitioning from institutions should be funded and in place prior to discharge, and a firm link between funding and plan components is needed. A consistent community reinvestment could be achieved if funds “followed” consumers into the community. Discharge planning and better consumer outcomes could also be achieved if 1) all discharges were to appropriate facilities with access to the services needed by the individual, and 2) there were minimum requirements (for example, three days) for notification to families and caregivers prior to discharge of persons with unmanageable behaviors.

Also, there is no uniform and equitable access to available services across Virginia, meaning that persons with disabilities often receive services based on where they reside, and not on what they need. In addition, many available programs, services and supports are simply not designed to achieve the goals of community integration.

Background and data: The lack of appropriate community-based services affects persons with disabilities in many negative ways. The team identified the following specific negative effects:

- Institutional forms of care are used when more effective, and perhaps less costly, community-based services may meet the person’s needs.
- Persons with disabilities and their families have few choices, and often no choices, about the care and supports they receive.
- Persons with disabilities in some parts of Virginia do not have access to services that are available to persons with similar needs living elsewhere in Virginia.
- Persons with disabilities who are not being served in the least restrictive setting appropriate to their needs are prevented from living in and being a part of their communities.

Relationship between the issue and current laws, regulations and policies: Many laws, regulations and policies are likely to be applicable to this issue, and the following are examples.

State:

The lack of appropriate community-based services is, in part, based on state policy and regulation. Virginia health care policy as a whole tends to overlook smaller, up-front preventive investments that could save significantly greater costs in the long term. This policy orientation is reflected in appropriations for human services and other supports. For example, focusing more attention and resources on preventing falls in the home by helping families pay for installation of handrails in bathrooms would significantly reduce later expenses resulting from hospitalization and nursing home placement for treatment of fall injuries. Similarly, respite care for families can delay placement in institutions with its attendant higher costs, as has been demonstrated by the model program at Eastern Virginia Medical School administered by the Southeastern Alzheimer's Association. Tele-medicine technology can bring service directly to persons in areas without providers (for example, for assessment) and can link providers without the necessity of traveling (for example, for discharge planning). Increased use of less costly in-home interventions and supports to persons with disabilities and their families can prevent institutionalization, strengthen the family's capacity to support their loved one at home, and hasten discharge of family members with disabilities from institutions to home. Other examples are evident throughout the service systems serving persons with disabilities.

Regulatory and funding procedures reinforce the policy orientation outlined above. For example, Virginia's reimbursement rates, as set in the State Medicaid Plan, limit the number and quality of available adult day care and home health care options.

Federal:

To some degree, state policy and regulations are reflective of federal policy and regulation. However, Virginia could take more advantage of opportunities for Waivers and other innovations that are afforded by Federal policy and regulation.

Other:

Services identified in discharge planning need to be in place prior to discharge.

Current programs and initiatives addressing the issue: There are many initiatives, programs, and services provided by many public and private agencies in Virginia, including some model programs, that have effectively increased the availability and capacity of community-based services, or which have increased access to such services and support for persons with disabilities and their families.

Disability populations impacted by the issue and how they are impacted: This issue impacts all disability populations.

Challenges:

1. Service infrastructure and design: The service systems for persons with disabilities are not focused on preventing unnecessary or premature institutionalization.

2. Appropriate targeting of services: Preventive services should be given more emphasis.
3. Role of providers and provider availability: There are not enough resources (i.e., funding, education and support) to attract, retain and sustain providers who offer adequate and broad ranges of high quality services.
4. Availability of community services and supports.
5. Service coordination among institutional and community providers: Service systems are complex and may include many providers. Service coordination is difficult to achieve, especially across systems, and especially for families.
6. Linkages with other service systems: Linkages between the systems providing health care and those providing services and supports for persons with mental disabilities and brain injuries are not well developed.
7. Monitoring and oversight: Monitoring and oversight of community programs is not comparable to the level of oversight of institutional care, and should be increased until it is comparable.
8. Funding: Additional funding is needed to expand capacity, availability and access to appropriate community-based services.

Options:

- PTOpII.1. Use various available administrative tools to address a particular issue or situation. Examples include instituting a training program; convening a workgroup; issuing an instruction; amending a regulation; and reorganizing a program.
- PTOpII.2. Use policy actions to change (or create or eliminate) a relevant policy, or policies, to address an issue.
- PTOpII.3. Use budget actions to acquire new or additional financial resources to address the situation, or change the allocation of resources within a budget(s).
- PTOpII.3.a Provide additional funding for expansion of community-based services in regular, planned appropriations. Advantages include an increase in the capacity of the system and serving new consumers. The disadvantage is that this requires new funds.
- PTOpII.3.b. Reallocate or restructure existing resources (i.e., move resources from other state programs into human services). The advantages are that no new funding is needed in the total state budget and, for human services, services available are more closely aligned with services needed. The disadvantage is that no new resources are added to system (i.e., total state budget).
- PTOpII.3.c Do nothing. This option is not an Olmstead Plan

PTOpII.4. Use legislative actions to generate legislative interest in the issue, change a relevant law or statute, or otherwise influence the legislative process in order to improve the situation or resolve the issue.

Recommendations and rationale for selecting the recommendations:

PTII.1. Provide additional funding for expansion of community-based services in regular, planned appropriations.

New funding is needed to expand community services and to strengthen and support existing services. The Commonwealth of Virginia and its citizens are in a position to generate new revenue streams for human services that support person with disabilities. This must be accomplished to prevent unnecessary or premature institutionalization and to ensure that all persons with disabilities can live in the least restrictive setting appropriate to their needs.

Additional Information: The following is the list of the specific community-based services gaps and needs which were identified by the team:

- Discharge planning – firm linkages of funding for plan components
- All required services and the funding to support them must be in place prior to the initiation of any placement.
- Consistent, long-term community reinvestment (funding follows consumers to the community).
- Develop effective respite care programs for caregivers, including necessary funding.
- Develop and enhance services, including short-term and long-term residential alternatives for those with severe behavior disorders.
- Services must be in place at the time of discharge or placement in both the facility and the community.
- Expand the use of telemedicine and tele-therapies for prevention and treatment.
- Utilize in-home supports as the first line of defense in prevention.
- Make available more adult day care and home health care options and other innovations of assisted care.
- Expand and make easily accessible the full range of supports needed in the community, including personal assistance services and emergency and short-term crisis services.
- Promote the development of independent living skills of individuals with disabilities to enhance community living success and to avoid admission or readmission to institutions.
- Develop and fund a coordinated system of education, training and employment services to support achievement of maximum independence in adult life for Virginians with disabilities.
- Make suicide prevention services accessible and visible throughout the state.
- Refer to appropriate care facilities and implement regulations in community-based facilities to provide a continuum of care within the system and three-day notification to family and caregivers prior to the discharge of unmanageable patients.

- Assure dependable, reliable personal assistants.
- Provide training and support to community providers serving individuals with disabilities, including development of, access to, and collaboration with behavioral analyst outreach teams throughout the state.

ISSUE III: HOUSING

DESCRIPTION OF THE ISSUE: *In order for people with disabilities to be independent within their own communities, there are issues that need to be addressed regarding housing. These issues include the following:*

- *A wide range of community housing stock and models of support should be developed to accommodate the individual living needs of people with disabilities (for example, housing complexes to accommodate family members and pharmacies and doctor's offices adjacent to care facilities).*
- *“Visitability” should be a major focus of housing reform (universal, physical accessibility—consideration of code changes). “Visitability” is a concept that would make not only the homes in which people with disabilities live, but all homes, visitable by people with disabilities including, but not limited to, features such as an accessible entrance, and an accessible restroom.*

Background and data: People with disabilities continue to be among the poorest in the Commonwealth. The Department of Housing and Community Development and Virginia Housing Development Authority November 2001 report on the *Analysis of Housing Needs in the Commonwealth* identified nine common statewide issues:

- There is a growing gap between income and housing costs for very low-income people.
- The shortage of affordable rental housing and existing housing options increase isolation.
- Much of the housing available to very low-income people is in poor condition.
- Very low-income people face limited location choices for affordable housing, and this restricts their access to services and employment.
- People who have disabilities or who are elderly and homeless have unmet needs for housing linked to services.
- Credit problems and inadequate financial management or life skills are barriers to purchasing a home and to obtaining adequate rental housing.
- There is a lack of public awareness and support for housing issues, therefore, affordable housing is not a local priority.
- Fiscal pressures on localities have caused housing to be viewed as a “cost,” and this has led to local barriers being imposed on affordable housing development.
- Changes are needed to local, state, and federal programs to better address housing needs.

Relationship between the issue and current laws, regulations and policies:

State: There are few incentives provided to housing developers to construct units that are affordable and accessible. There are a variety of barriers to accessing assistance, including inflexible program guidelines that limit participation and preclude some needs.

Federal: Fair Housing laws are not enforced. There are few incentives provided to housing developers to construct units that are affordable and accessible. There are a variety of barriers to accessing assistance including inflexible program guidelines that limit participation and preclude some needs.

Other: Numerous local zoning, regulatory and fee requirements are being imposed on housing, for example:

- Limited zoning for multifamily housing;
- Minimum lot sizes and a variety of restrictive covenants for single family homes; and
- Imposition of impact fees, proffers and utility hook-up fees.

There is a growing “not-in-my-backyard” (NIMBY) attitude that undercuts resolution of critical unmet needs.

Current programs and initiatives addressing the issue:

1. *The Low Income Tax Credit (LITC)*, administered by VHDA: provides 50 points for constructing a certain number of super accessible units in a LITC project.
2. *Voluntary, private or public civic organizations* such as AARP, KOVAR, the Centers for Independent Living and Area Agencies on Aging, often will make home modifications at no or low cost, based on financial support from fundraising or grants, for example, Community Development Block Grants.

Disability populations impacted by the issue and how they are impacted: This issue impacts all disability populations.

Challenges:

1. Service infrastructure and design
2. Federal program issues
3. Appropriate targeting of services
4. Role of providers and provider availability
5. Availability of community services and supports
6. Monitoring and oversight: Current Fair Housing laws are not being enforced.
7. Data/information system issues

ISSUE IV: EDUCATION/PUBLIC RELATIONS

DESCRIPTION OF THE ISSUE: *The basic issue is one of communicating the training, education, and resources to professionals, families, consumers, and surrogates to use as appropriate.*

Background and data: There are not enough venues (or common vocabularies) to share information, particularly within necessary timeframes. The following are needed to address this issue:

- Disability specific training for public safety personnel and planning with public safety;
- Better communication among doctors, consumers, families, caregivers and existing community services;
- Information and referral to appropriate services;
- Improvement in the quality and quantity of information to families and consumers, including “how tos” and the process of communication;
- Public education on the importance of long-term care insurance policies with confined care riders to help reduce escalation costs to taxpayers;
- Training for families in best practices for successful interactions with persons with disabilities;
- Education of discharge planners, health departments, and state agencies about Virginia’s waivers; and
- Promotion of the development of a larger pool of skilled professional staff (for example, physicians, specialist such as gerontologists, and RNs) and paraprofessional staff (for example, CNAs and direct care workers) through aggressive recruitment and training efforts, including pre-service and in-service training based on national and state-wide standards and up to date curricula, targeted toward improving quality of care for people with disabilities in facilities and the community to prevent premature and unnecessary institutionalization.

Relationship between the issue and current laws, regulations and policies:

Federal: P.L. 94-142-- Lack of enforcement
IDEA

Current programs and initiatives addressing the issue:

1. *Private and civic organizations* provide proper training, support (information and referral services).
2. *Genetic screenings.* Pre-, peri-, and post-natal screenings, as well as follow-up care.
3. *Road map to systems change* developed by the Executive Branch.

Disability populations impacted by the issue and how they are impacted: Timely referral and treatment are crucial in positive outcomes and treatments for all disability populations.

Challenges:

1. Service infrastructure and design: In multiply-impacted populations, different processes are used.
2. Federal program issues: Housing vouchers (particularly Section 8) may not be able to be held if hospitalization or institutionalizations are needed.
3. Appropriate targeting of services
4. Availability of community services and supports: Waiting lists exist for all services and often are not flexible for individual needs.
5. Service coordination among institutional and community providers: Scheduling issues and timeframes are sometimes incompatible.
6. Data/information system issues: Technology information is not in place for systems to “talk” to each other.

ISSUE V: TRANSPORTATION

DESCRIPTION OF THE ISSUE: *In order for people with disabilities to be independent within their own communities there are issues that need to be addressed regarding transportation. These issues include the following:*

- *Regulations and training regarding the transportation of people with disabilities; and*
- *Affordable, accessible transportation.*

Background and data: There is very limited--or no--public transportation in rural areas. Most localities provide the minimum paratransit service required under the Americans with Disabilities Act (ADA). Lack of public transportation for individuals with disabilities who are dependent on public transportation limits where those individuals can live, work and recreate.

Relationship between the issue and current laws, regulations and policies:

State: The majority of State funds provided by the Federal government are spent on road repair and/or construction. Only a small portion is used for public transportation. The State formula needs to be changed to allow additional funds to be spent on public transportation.

Other: Public transportation is covered under the ADA, which requires that paratransit be provided within $\frac{3}{4}$ of a mile of public transportation lines. Most localities that provide paratransit provide the minimum required by the ADA.

Current programs and initiatives addressing the issue:

1. *Wheelchair securement training* is provided to human service, private, public providers by the Community Transportation Association of Virginia (CTAV) and Community Transportation Association of American (CTAA).

2. *Investigating provider certification:* Providers who meet various criteria are certified to a certain level by CTAV.
3. *ADA compliance:* The Department of Medical Assistance Services (DMAS) requires that all Medicaid transportation providers are ADA compliant.

Disability populations impacted by the issue and how they are impacted: This issue impacts all disability populations.

Challenges:

1. Service infrastructure and design
2. Federal program issues
3. Appropriate targeting of services
4. Role of providers and provider availability
5. Availability of community services and supports
6. Monitoring and oversight
7. Data/information system issues

ISSUE VI: MEDICAL /MEDICAID

DESCRIPTION OF THE ISSUE: *The following issues were identified:*

- *Maximize Medicaid funds for use in transition and enhancement;*
- *Serve non-Medicaid Eligible Population;*
- *Provide affordable home care;*
- *Medicaid policy reform; and*
- *Lack of funding for employment services through waivers.*

Background and data:

- Medicaid funding should be available for transition services and costs. Medicaid funds should be used to support an individual's transition from an institution to the community (as is done in other states).
- A significant number of people in institutions and/or in danger of unnecessary and premature institutionalization are not eligible for Medicaid. These individuals require the same supports that those on Medicaid will have available. A state plan to address the needs of only people eligible for Medicaid would leave a significant number of people without the supports they need to leave institutions and to function in the least restrictive living situation of their choice.
- Individuals are unable to utilize home care due to the co-pay. In addition, higher allowable expense limits need to be established as well as flexibility regarding pooling of Personal Assistance Service hours.
- Current Medicaid policy/philosophy is based on a medical model. The health and well-being of a person with disability goes beyond specific ailments, just as it does with a person without disability. Persons with disabilities are affected by their

environment, mental health, social life and a variety of other factors. In many cases, these non-medical issues – if not addressed – result in medical problems. Under current policy, many essential biopsychosocial needs cannot be provided for an individual, even when the services would greatly impact the individual's ability to remain in the least restrictive environment.

- Employment services are essential needs for people with disabilities and must be included in all waivers (with the exception of the Elderly and Disabled waiver and all future Dementia Waivers).

Current programs and initiatives addressing the issue:

Medicaid and Medicaid Waivers, administered by DMAS. The mechanism is already in place for addressing each of these issues.

Disability populations impacted by the issue and how they are impacted: Each of these issues reaches across all disabilities and affected groups. Recommended changes would expand and enhance the supports available to individuals with disabilities and increase the likelihood of successful placement in the community. While there would be an expansion of services available, there is not necessarily a corresponding increase in program costs.

Challenges:

1. Service infrastructure and design to be altered: Need for administrative flexibility. DMAS needs to amend waivers to include transition services.
2. Federal program issues: Policy and philosophy changes
3. Appropriate targeting of services: Expand service options
4. Role of providers and provider availability: Workforce issues (including reimbursement rates, compensation and training)
5. Availability of community services and supports: Reimbursement rates need to be increased.
6. Service coordination among institutional and community providers: Smooth transitions of both services and supports; examination of catchments areas
7. Linkages with other service systems: Funds must be tracked and funding/service tracks must be established.
8. Monitoring and oversight: Ensure that funds remain available; services are affordable; and new policy is implemented.

Recommendation:

- PTVI.1. Shift Medicaid state and federal policy towards a biopsychosocial model (with a community focus).

ISSUE VII: FUNDING

DESCRIPTION OF THE ISSUE: *Adequate funding for needed programs and services is critical to the prevention of premature, inappropriate or unwanted institutionalization of Virginians with disabilities. A number of programs and services need to be developed and funded to address unmet needs. The development of these programs and services could also support the transition of people with disabilities to the least restrictive setting appropriate to their needs. Expanded funding for some existing services is also needed. Finally, adequate funding must be made available to ensure that providers of services, both public and private, are fairly compensated for services provided so that services are accessible in all communities in the Commonwealth of Virginia.*

Background and data: Adequate, routine funding will ensure that Virginians with disabilities are afforded the opportunity to receive the services and supports that they require in the least restrictive settings appropriate to their needs, and provide the maximize benefit for both the individual and the Commonwealth. Many people could manage their lives with relatively low levels of support if they had assistance to manage the public benefits that they receive. State level funding to support administrative costs associated with this type of assistance would provide this support to individuals with disabilities without requiring them to pay for the service out of their meager benefit allowances. Inaccessibility of services is closely tied to the inadequacy of funding and contributes to out of home placements that are premature or undesirable. In a large state like Virginia, there are many remote rural communities where services can be difficult to access, often due to a lack of community service providers. In order for providers, whether public or private, to establish business operations in a community with low population density, financial support should be identified by the state to offset the costs of business development and service provision. Inaccessibility of services is also impacted by the insufficiency of reimbursement rates paid to providers of service in the Commonwealth. Many individuals in the state find themselves on waiting lists for services, even when they have approved funding, because providers of services cannot afford to provide the service given the current reimbursement rates. This problem is particularly acute in Virginia's more urban areas, where the cost of providing services is greater due to such factors as the higher cost of staff salaries and property rentals. The cost of care in these areas is also impacted by the need for personnel who are able to respond to the diverse language needs of the populations who reside there. Reimbursement rates should be based on methodologies that are responsive to regional differences in the cost of services provided. While people with disabilities assert their rights to live and receive services and support in the settings that are their preference and that best support them, they remain more vulnerable to abuse neglect and mistreatment than most citizens of the Commonwealth. The need to fully fund protective services has to be addressed with equal consideration to the funding of services provided.

Relationship between the issue and current laws, regulations and policies:

State: In cases in which unrestricted funds are available in a department, funding issues often can be addressed through changes in regulation without legislative action. When new or additional funding is needed, this has to be addressed by legislative action.

Current programs and initiatives addressing the issue:

1. In *Caregiver programs*, nominal funds are provided to caregivers to offset the cost of care.
2. *Medicaid Waiver Programs and Medicaid State Plan Services* administered by the Department of Medical Assistance Services (DMAS).
3. *Protective Services for Vulnerable Citizens*: VOPA provides protection and advocacy services; Department of Social Services' Adult Protective Services and Children's Protective Services; Office of the Inspector General provides general oversight in state mental health and mental retardation facilities; Licensing of Community Programs; Ombudsman Program, and the DMHMRSAS Human Rights program.

Disability populations impacted by the issue and how they are impacted: This issue impacts all disability populations.

Challenges:

1. Service infrastructure and design: Services are not designed to address the prevention of unnecessary or premature out-of-home placements or to support transitions to the least restrictive setting appropriate to their needs. Often, services become available only after an individual reaches a severe crisis. At that point services are the most costly and potentially the least appropriate because they were obtained under crisis conditions and without careful planning.
2. Appropriate targeting of services: Prioritization of services is an issue. The system is trying to catch up to the service needs of the community that are at a critical state, while also attempting to implement changes that will address prevention. The financial commitment that this requires is a significant challenge.
3. Role of providers and provider availability: Providers are having great difficulty in providing services, given current reimbursement rates. Without planned, regular and predictable rate increases, this situation will worsen. Many providers are refusing to serve additional people, congregating increasing numbers of people together for service, and discharging some individuals who present with complex needs.
4. Availability of community services and supports: The challenge of attracting providers to remote communities is a continuing problem. Providers that are already feeling a severe pinch with the low reimbursement rates in the state are unable to expand into new areas. It is also difficult to attract and retain providers in the more urban areas, given the high cost of services provided and the low reimbursement rates. The absence of regular COLA increases in reimbursement rates also severely impacts the financial stability of providers.
5. Service coordination among institutional and community providers: Funding should follow the person, but care must be given to preserving the complete array of services needed. Virginia should look toward "integrated funding" rather than agency or department specific funding.
6. Linkages with other service systems
7. Monitoring and oversight: As people with disabilities are served in the least restrictive setting appropriate to their needs, which for some may include transition

from facility to community care, the need for monitoring, oversight and protection will grow. Monitoring and oversight in the community and in the state's facilities should be comparable to ensure quality care, and so that families can feel assured of the safety and security of their loved ones. Correspondingly, the need for funding for the entities charged with providing these protections will increase.

8. Data/information system issues: Resources can be maximized in Virginia through the use of such technological innovations as tele-medicine and tele-therapy. Appropriate funding for a long-term monitoring system is also critical in Virginia.

Options:

PTOpVII.1.a. Expand funding for the caregiver grant program.

This allows family members or other caregivers to continue providing care.

PTOpVII.1.b. Develop and expand payee program

This allows people to have the support they need without invading merger benefits

PTOpVII.2. Establish adequate and equitable rates for services provided with provision for cost of living adjustments.

Services would be available to people requiring them, and new providers would be attracted to, and retained in, Virginia.

PTOpVII.3 Establish a position or office at the state level to assist with provider development in underserved communities.

This would create a focused effort to develop services in all parts of the state and provide private/public partnership opportunities.

PTOpVII.4. Fully fund full staffing of all protective services.

People with disabilities will be better protected from harm and discrimination, both of which can lead to deprivation of the right to receive services in the least restrictive setting appropriate to the person's needs.

Recommendations and rationale for selecting the recommendations:

PTVII.1.a. Expand funding for caregiver grant program.

This program prevents premature or undesirable out of home placements and can be used to support transitions to the least restrictive setting appropriate to the person's need.

PTVII.1.b. Develop and expand payee program.

This program allows people who only require benefits management assistance to live independently to get that assistance without paying for it from their benefits allowance – needed to avoid premature or unneeded placements and also to support transitions to the least restrictive setting appropriate to the person’s need.

PTVII.2. Increase reimbursement rates for providers of service.

Current rates are inadequate to cover the cost of care provided. Some services are rarely provided due to the inadequate reimbursement rates. The challenges of workforce shortages are exacerbated by inadequate rates.

PTVII.3. Develop a position or office at the state level to assist public and private providers with funding to expand into unserved and underserved areas of Virginia.

If people with disabilities have access to services in their home communities, they will be less likely to require premature or unnecessary institutional care or will require such care much later. Those people who can transition to the least restrictive setting (appropriate to care they need) can do so more easily when services are made available in their home communities.

PTVII.4.a. Fully fund all protective services.

People with disabilities and their families will feel more comfortable with community care if they are assured of full protection.

PTVII.4.b. Expand VOPA’s personnel to provide full representation to persons with disabilities.

ISSUE VIII: LEGISLATION

DESCRIPTION OF THE ISSUE; BACKGROUND INFORMATION AND DATA:

- *There are insufficient funds to provide individualized supports for individuals with disabilities.* This is an issue because some persons with disabilities who need these supports cannot get them.
- *Too little is invested in disability or disease-specific scientific research aimed at prevention, treatment, cure or recovery as possible.* This is an issue because advances in preventing the antecedents of disability or in treating disabling conditions effectively or in enabling cure or recovery will improve the quality of life for all Virginians and reduce the costs of disability over the long-term.
- *Privacy protections for genetic information related to predisposition for disabling condition are insufficient.* This is an issue because weaknesses in privacy protections for genetic information can discourage persons who have predisposing conditions from taking advantage of genetic testing, counseling and therapies that can help

reduce the incidence or impact of subsequent disability. Weaknesses in privacy protections for genetic information also lead to discrimination.

- *Eligibility requirements for nursing home, rehabilitation hospital, and ICF/MR services are too restrictive and hamper access to waivers and community-based services.* This is an issue because eligibility requirements for the waiver services that prevent persons from needing nursing home, rehabilitation hospital or ICF/MR facility care are the same as the requirements for admission to those facilities. It does not make sense for persons to have to become so severely disabled in order to qualify for the services that would have prevented that level of disability.
- *State code requirements and legal system practices often work against use of prevention alternatives.* This is an issue because judicial officials may override professional judgment and recommendations, therefore biasing dispositions in favor of hospitalization.
- *Insufficient telemarketing fraud protection leaves consumers vulnerable to abuse.* This is an issue because consumers are vulnerable to telemarketing fraud without increased protections.
- *Psychiatric advance directives are not well known nor widely used, and might support better treatment experiences and outcomes if used when applicable.* This is an issue because expanded use of psychiatric advance directives might reduce the use of hospital care for persons in crises.
- *Funds for deposits, household goods, and so forth are not usually available to consumers who are eligible to receive services. This reduces utilization of much needed services.* This is an issue because these necessities must be in place in order to move into a community living situation. Currently, residents often cannot keep enough of their benefit payments to pay for these necessities upon transitioning out of institutions.
- *Locally based entities are not in place to meet future community needs.* If the Commonwealth demonstrates and implements, through policy and funding, a commitment to building locally-based entities to meet future community needs, services will be enhanced.
- *The health care system has no dedicated revenue source, which makes the system vulnerable to cyclic funding, and periods of strength and weakness.* This is an issue because the lack of a dedicated revenue stream puts critical --sometimes life and death--healthcare services at the whim of the economy.
- *Insurance companies often fail to pay claims within a reasonable amount of time (for example, two to three weeks as opposed to two to three months), even when the claim is upheld.* This is an issue because it delays payment for services rendered. Addressing this issue will result in insurance companies paying undisputed, valid claims more promptly.
- *There are too few school-to-work transition activities available through adult service providers.* This is an issue because when children with disabilities age out of school, they should not have to stop receiving the services that have helped them to live in the least restrictive setting appropriate to their needs.
- *People with disabilities do not have access to a prescription drug benefit.* This is an issue because people with disabilities often cannot afford their prescriptions, which reduces their quality of life and increases the risk of death or disability and the

associated costs to the system. This puts the Commonwealth in a morally compromised position regarding what it deems to be an acceptable burden for persons without insurance versus those who have coverage.

- *Reimbursement rates usually stay the same, while expectations for service delivery go up. Rates should go up accordingly and, as expectations for service delivery (and reimbursement revenues) increase, appropriate increases in oversight also need to be developed (for example, through agency licensing, Child Protective Services (CPS) and Adult Protective Services (APS), the Virginia Office of Protection and Advocacy (VOPA); the DMHMRSAS Human Rights and Licensing programs, and the Office of the Inspector General). This is an issue because serving increasingly complex needs of persons with disabilities requires commensurate oversight.*

Relationship between the issue and current laws, regulations and policies: Some of these issues are governed by state law, regulation or policy, and others are governed by federal law, regulation or policy (for example, Medicare and prescription coverage).

Current programs and initiatives addressing the issue: There are insufficient initiatives to address these issues (for example, The Alzheimer's and Related Disease Research Award Fund is one of few such programs, and it is insufficiently funded).

Disability populations impacted by the issue and how they are impacted: Many of the above legislative issues affect particular groups of persons with disabilities more than others. For example, privacy protection for genetic information affects persons with disabilities for which there is a genetic factor. Psychiatric advance directives affect persons with psychiatric disabilities. Enhanced accountability for insurance companies affects persons with insurance. Transition services and supports affect young persons coming out of high school who are transitioning to adulthood. The burden of these issues, however, falls on all Virginians.

Recommendations and rationale for selecting the recommendations:

- PTVIII.1. Appropriate new funding for disease-specific research (similar to the Alzheimer's and Related Diseases Research Award Fund) in order to leverage additional funds from other fund-granting research entities.
- PTVIII.2. Initiate a study to develop recommendations for strengthening protections for privacy of genetic information, with the goal of encouraging increased use of genetic testing and subsequent genetic therapy where available, as well as family health care planning by families or persons with predisposing conditions that can lead to disability if left untreated.
- PTVIII. 3. Liberalize eligibility requirements for nursing home, rehabilitation hospital and ICF/MR waivers to encourage use of the least restrictive settings appropriate to the needs of persons with disabilities.

- PTVIII.4. Provide funding to implement an educational campaign aimed at persons with psychiatric disorders and their services providers to increase the use of advance directives.
- PTVIII.5. Amend appropriate statutes to ensure that judges and magistrates more effectively integrate professional recommendations into their decisions about hospitalization, with the goal to reduce unnecessary or premature institutionalization.
- PTVIII.6. Maximize the use of expertise currently in facilities for persons with mental retardation by expanding the “Regional Community Support Center” concept, now in place at Northern Virginia Training Center, to all such facilities.
- PTVIII.7. Allocate sufficient funding to establish a revolving fund for persons with disabilities in institutions to use for utility and rent deposits, and other up-front household expenses associated with community living, to enable them to move from institutions to more integrated community settings.
- PTVIII.8. Establish in the Appropriations Act a dedicated revenue stream for health, mental health, rehabilitative and other services and supports for persons with disabilities (similar to that of the Lottery for K-12 Education).
- PTVIII.9. Appropriate funding to expand transition activities for young persons with disabilities.
- PTVIII.10. Study and recommend options for the Commonwealth to establish a prescription drug assistance program for persons with disabilities.
- PTVIII.11. Study the appropriateness of oversight in relation to individual needs, services provided and reimbursement received.

These are samples of recommendations for legislative action. There are many more that could be developed to address these issues.

ISSUE IX: EXPANSION AND COLLABORATIONS

DESCRIPTION OF THE ISSUE: *Expansion of the current treatment system capacity, as well as improved collaboration among all of the stakeholders within the system, are viewed as significant issues.*

Background and data: Many services are needed, such as home help and companion services; abuse, neglect and fraud protections; adult foster care; hospice and other palliative care; “family access” public restrooms; and increased placement options of every kind. In addition, increased collaboration is needed at all levels to improve

planning and service coordination, especially when transitions from one system to another are contemplated or implemented.

Relationship between the issue and current laws, regulations and policies: These issues are affected by state regulations and policies, as well as a necessary shift in philosophy at all levels of administration to more actively encourage interagency collaboration in development and evaluation of community-based services.

Current programs and initiatives addressing the issue:

Regional Community Support at NVTC: Enables treatment centers to share medical, dental, and therapeutic expertise with those who either cannot access comparable care in the community or cannot afford it.

Disability populations impacted by the issue and how they are impacted: This issue impacts all disability populations.

Challenges:

1. Service infrastructure and design: Expansion of services necessary to shift adequate resources into communities.
2. Appropriate targeting of services: Expansion of services based on quality needs assessment should refine targeting of services.
3. Role of providers and provider availability: Collaboration would be inherent in the culture of service provision as an expected activity for performance evaluation.
4. Availability of community services and supports: Current gaps would be addressed by providing expanded services.
5. Service coordination among institutional and community providers
6. Linkages with other service systems

Recommendations and rationale for selecting the recommendations:

- PTIX.1.a. Expand Department of Social Services (DSS) companion program with emphasis on provision of home help for persons with sensory disabilities and others who do not currently qualify for waivers.
- PTIX.1.b. Expand Programs to combat abuse, neglect, and exploitation, including consumer fraud.
- PTIX.1.c. Expand Availability, use, and oversight of adult foster care.
- PTIX.1.d. Expand Accessibility of hospice services, with expansion of palliative care services.
- PTIX.1.e. Expand Use of current expert models already in place (for example, the Regional Support Center at NVTC).

- PTIX.1.f. Expand Availability of “family access” restrooms in public places (for example, highway rest stops and public buildings).
- PTIX.1.g. Expand Increased placement options at identified levels of the continuum.
- PTIX.2.a. Improve collaboration emphasis: Avoid duplication of effort by connecting existing services and programs whenever possible (for example, suicide prevention).
- PTIX.2.b. Improve collaboration emphasis: Maintain community ownership and accountability of the treatment process clinically, financially, and legally.
- PTIX.2.c. Improve collaboration emphasis: Make quality services available uniformly across the state, with an emphasis on choice and meeting individual needs at the time of discharge or transfer.
- PTIX.2.d. Improve collaboration emphasis: Require all transitions from one service to another to be preceded by planning meetings that include the individual, his or her surrogate decision-maker if applicable, staff from the discharging and receiving service providers, and any other persons whom the individual or surrogate decision-maker selects.

F. REPORT OF THE QUALIFIED PROVIDERS TEAM

Team Chair: John Toscano

**Team Recorders: Steve K.Waldron
Karen Tefelski**

Agency Convener: Jonathan Martinis, Virginia Office for Protection and Advocacy (VOPA)

The Qualified Providers team was representative of, and considered the interests of all disability populations in its work.

Vision and values:

Qualified providers, for the purposes of the Olmstead implementation effort in Virginia, are or can be individuals or organizations that have a variety of backgrounds, professional expertise and skills that maximize the ability and capacity of an individual with disabilities to live independently in the community of his or her own choice with a quality of life that empowers him or her to fully participate in society.

ISSUE I: ACCESSIBILITY OF QUALIFIED PROVIDERS

DESCRIPTION OF THE ISSUE: *Some individuals with disabilities have inadequate physical, communication, transportation, cognitive, and language accessibility to qualified providers.*

Disability populations impacted by the issue and how they are impacted: All populations are impacted.

Challenges:

1. Service infrastructure and design
2. Federal program issues
3. Availability of community services and supports

Recommendations and rationale for selecting the recommendations:

QPI.1. Address the lack of transportation for consumers with disabilities by increasing the: a) use of telemedicine; b) provision of services at places convenient to consumers; and c) efficiency and coordination of transportation, including sharing of resources by agencies and programs.

Transportation has been identified as a significant barrier to accessing services. This will increase consumer choice and accessibility and the availability of qualified providers.

QPI.2. Increase funding and reimbursement for transportation services.

Transportation has been identified as a significant barrier to accessing services. This will increase consumer choice and accessibility and the availability of qualified providers.

QPI.3.a. Require providers to be physically accessible to consumers and families and in full compliance with the Americans With Disabilities Act (ADA) and the ADA Accessibility Guidelines (ADAAG) to be considered qualified.

QPI.3.b. Require providers to ensure communications access to consumers and families, including providing sign language interpreters, alternate formats and other appropriate communication supports and services, in full compliance with the ADA to be considered qualified.

QPI.3.c. Require providers to ensure cognitive accessibility so that consumers with cognitive disabilities, their family members and advocates are given the maximum opportunity to understand their rights and make informed choices.

QPI.3.d. Require providers to be language accessible by ensuring that non-English speaking consumers are given the maximum opportunity to understand their rights and make informed choices.

This will ensure maximum consumer accessibility and choice.

ISSUE II: CHOICE VALUES AND PARADIGMS

DESCRIPTION OF THE ISSUE: *The Consumer/Family choice paradigm and values are not fully infused into the services systems in Virginia.*

Background and data: Without real choice, consumers and families are less likely to be treated as respected customers in a market driven system.

Disability populations impacted by the issue and how they are impacted: All populations are impacted.

Challenges:

1. Service infrastructure and design
2. Federal program issues
3. Role of providers and provider availability
4. Service coordination among institutional and community providers
5. Linkages with other service systems

Recommendations and rationale for selecting the recommendations:

QPII.1.a. Encourage and increase use of technology to support greater consumer and family choice and independence.

This would increase choice of providers for consumers and families and lower costs by using technology rather than paid staff.

QPII.1.b. Increase available providers by enabling greater provider competition, which will lead to greater consumer and family choice.

QPII.2. Virginia needs a dedicated funding stream.

The system would be dramatically improved in both quantity and quality of providers if providers have sufficient funding incentives to provide service.

QPII.3. Streamline regulations and paperwork.
and 4.a.

QPII.3. Investigate consolidating some of the licensing regulations.
and 4.b

QPII.3. Simplify regulations.
and 4.c.

These will give providers more time and opportunity to serve consumers.

QPII.4.d. Ensure that consumers have access to different levels of care and support, including congregate settings.

This supports choice.

QPII.5. Encourage and increase the use of technology to support greater consumer and family choice and independence, and provide linkages between consumers and providers over distances.

This would:

- Increase choice of providers for consumers and families;
- Increase access to providers;
- Lessen travel time; and
- Allow providers to serve more people.

ISSUE III: CONSUMER, FAMILY, ADVOCATE, AND PUBLIC TRAINING NEEDS

DESCRIPTION OF THE ISSUE: *Consumers, families, advocates, and the public are often not aware of consumer rights.*

Background and data: Consumers are not consistently made aware of and/or adequately explained their rights.

Disability populations impacted by the issue and how they are impacted: All populations are impacted.

Challenge:

1. Service infrastructure and design

Recommendations and rationale for selecting the recommendations:

QPIII.1.a. Assure that consumers have their discharge rights and that consumers, families and advocates have their rights to meaningfully participate in the consumer's discharge planning from the date of the consumer's admission.

QPIII.1.b. Implement statutory and regulatory requirements for display of documents outlining consumer rights.

QPIII.1.c. Create, make available, and distribute brochures on rights (including discharge rights, durable power of attorney, least restrictive setting, and assigning rights.).

These would ensure that consumers, families and advocates are aware of their rights.

ISSUE IV: DATA & MONITORING NEEDS

DESCRIPTION OF THE ISSUE: *Virginia needs a method to assess and monitor the implementation of Olmstead and provide guidance for future implementation and funding needs.*

Background and data: Olmstead Plan implementation will take time and may encounter delays. Government and policy makers may tend to forget Olmstead-type initiatives. The General Assembly generally will not bind future General Assemblies by dedicating funds to be used in the future. Changing needs of people with disabilities necessitate that the Plan be dynamic (i.e., able to be modified as times and needs change and evolve).

Identification of the disability populations impacted by the issue and how they are impacted: All populations are impacted.

Challenges:

1. Service infrastructure and design
2. Appropriate targeting of services
3. Service coordination among institutional and community providers
4. Linkages with other service systems
5. Monitoring and oversight
6. Data/information system issues

Recommendations and rationale for selecting the recommendations:

QPIV.1., 2., 3. and 4. Establish ongoing Olmstead review and analysis of progress of implementation of the Olmstead plan. Review and analysis should be performed by a body external to the Executive Branch. Review and analysis will be used by the Olmstead Taskforce to provide regular input to the General Assembly and the Administration on implementation methods and funding needs.

The Olmstead Taskforce should have a continuing role in the implementation, modification, and funding of the Plan to ensure continuing input by consumers, families, and advocates.

ISSUE V: WORKFORCE CRISIS

DESCRIPTION OF THE ISSUE: *There is no system in Commonwealth that adequately pays, trains or encourages people to become direct support professionals.*

Background and data: The Commonwealth should recognize that this is a public policy issue that includes a need for resources. We should recognize and acknowledge there are non-Agency, non-regulated, non-licensed care providers who do not receive public funds for their services and who provide support to individuals in their homes and their communities. We are focused on only public money, but these individuals can benefit from training and support. We should focus on supporting a market driven system.

Disability populations impacted by the issue and how they are impacted: All populations are impacted.

Challenges:

1. Service infrastructure and design
2. Federal program issues
3. Appropriate targeting of services
4. Role of providers and provider availability
5. Availability of community services and supports
6. Service coordination among institutional and community providers
7. Linkages with other service systems
8. Monitoring and oversight
9. Data/information system issues

Recommendations and rationale for selecting the recommendations:

- QPV.1.a. Provide adequate compensation and benefits.
- QPV.1.b. Train and hire consumers and other persons with disabilities.
- QPV.1.c. Provide State support for benefit packages.

Because of currently low compensation and inability to make livable wage, these would serve to develop and attract more competent direct care professionals to this field.

- QPV.2. Increase reimbursement rates to providers and make changes to policies to include increased wages/benefits to direct support professionals.

This would develop and attract more competent providers to this field.

- QPV.3. To address the lack of appropriate career advancement opportunities (for example, nursing levels based on training):
- Develop a direct support standardized certificate training program and offer it in a variety of venues such as community colleges, agencies, Internet based, and continuing education;
 - Title direct care as “Direct Support Professional;” and

- Make training open to non-agency, non-regulated, non-licensed care providers.

This would develop and attract more competent direct care professionals to this field.

QPV.4., 5., 6., and 7. Move toward a market based system where providers pay and are paid for services according to what they are actually worth.

This would develop and attract more competent providers to this field.

ISSUE VI: FUNDING

DESCRIPTION OF THE ISSUE: *An adequate and appropriate array of quality services is not fully funded.*

Background and data: Providing for consumers is a core responsibility of the Commonwealth. It is inherently unfair for the Commonwealth to divest itself of this responsibility by requiring the private sector and local governments to do so.

Disability populations impacted by the issue and how they are impacted: All populations are impacted.

Challenges:

1. Service infrastructure and design
2. Federal program issues
3. Linkages with other service systems
4. Monitoring and oversight
5. Data/information system issues

Recommendations and rationale for selecting the recommendations:

- QPVI.1.a. Provide adequate funding to eliminate waiting lists.
- QPVI.1.b. Provide for funding that anticipates regular increases in the need for services in order to avoid future waiting lists.
- QPVI.1.c. Provide sufficient funding to meet the cost of providing services.
- QPVI.1.d. Provide funding to guarantee an increase in the rate paid to providers that allows for increases in inflation or increases in the cost of providing services.
- QPVI.1.e. Provide funding to ensure that mechanisms are in place to promote and maintain an adequate and skilled workforce.

These will ensure that there are adequate and appropriate community based services available. They will also encourage more providers to enter this field and encourage increased consumer and family choice and provider competition.

QPVI.2. Maximize availability and use of federal funds, including Medicaid and vocational rehabilitation funding.

This will ensure that there are adequate and appropriate community-based services available. It will also encourage more providers to enter this field and encourage increased consumer and family choice and provider competition.

QPVI.3. Explore funding through increased general funding, provider licensing fees, and cost saving methods, including increased use of technology and streamlining of regulations or consolidation of regulatory oversight.

This will maximize available funding and minimize direct costs to the Commonwealth.

ISSUE VII: LAW AND REGULATIONS

DESCRIPTION OF THE ISSUE: *Virginia lacks consistent and appropriate statutes and regulations that protect the rights of consumers and provide for consumer choice, provider competition, and increased supports and services.*

Background and data: Currently, statutes and regulations are not always consistent and may serve as a barrier to qualified providers who would otherwise want to enter this field.

Disability populations impacted by the issue and how they are impacted: All populations are impacted.

Challenges:

1. Service infrastructure and design
2. Service coordination among institutional and community providers
3. Linkages with other service systems
4. Monitoring and oversight

Recommendations and rationale for selecting the recommendations:

QPVII.1. There should be one definition of “qualified provider” to be applied by all regulatory agencies of the Commonwealth. The definition agreed upon by the Team is as follows: A Qualified Provider is an individual or organization that provides goods, supports, and/or services and that meets the following *minimum qualifications*:

- Is competent to provide goods, supports, and/or services and has the resources needed to provide individualized services to the individual;
- Has the ability to assess the needs of the individual with the active participation of the individual;
- Meets the needs of the individual to be served; and
- Complies with State and Federal law.

Under this definition the following *presumptions of qualification* would apply:

- If the provider of goods, supports, and/or services is licensed or certified to practice in that profession or field, the provider is presumed to be qualified.
- If the provider is an employee of or contractor for a state agency, the provider is presumed to be qualified to provide goods, supports, and/or services for which she or he is employed or contracted.
- If the provider of goods, supports, and/or services belongs to an unlicensed or unregulated profession or field, the provider is presumed to be qualified if the individual and provider agree in writing that the provider meets the definition for a qualified provider.

Under this definition, the funding entity (i.e., the Commonwealth) could decide not to approve funding payment to a provider only as follows:

Determination of Qualification:

- The funding agency could challenge the qualifications of a provider of goods, supports, and/or services only by producing specific evidence to prove that the provider is not qualified.
- The funding agency or entity makes the determination of whether the provider of goods, supports, and/or services is not qualified with the active participation of the individual and/or the individual's family members or advocates. The evidence should be individualized on a case-by-case basis.
- The individual would have a right to appeal this determination, including a final appeal in Court.

There should be a system to protect and provide for substitute decision makers for persons who lack the legal capacity to make the choices required by the above definition of qualified provider, as well as other choices and decisions. Any law, policy, or regulation that inhibits either access to qualified providers or the increase in the number of qualified providers should be examined and rewritten to eliminate the inhibition.

This definition will allow for maximum consumer choice, while also providing safeguards to ensure that payment is not made to unqualified providers. This is a market-based model that gives greater control to the consumer and family. While there is already a legal requirement that the Commonwealth provide substitute decision makers, it is not consistently met.

- QPVII.2.a. There should be an increase in the use of individually/disability based outcome measurements.

This will ensure that oversight focuses on results.

- QPVII.2.b. Because the definition of qualified providers would apply across the board, the Commonwealth should consolidate the regulatory function of disability agencies (for example., combine licensing functions).

This will provide greater consistency and a substantial cost savings to the Commonwealth.

- QPVII.3. There should be strong accountability measures, including the ability to sue and recover funding from providers who commit fraud related to their qualifications or mislead consumers into believing that they are qualified.

This will provide safeguards to ensure that unqualified providers are not operating freely in the system.

ISSUE VIII: LICENSED PROFESSIONALS

DESCRIPTION OF THE ISSUE: *There is an inadequate supply of Licensed Professionals.*

Background and data: There is a decline in number of doctoral faculty who provide academic professional training; lack of interest in providing community disability services; and lower respect for the nursing profession.

Disability populations impacted by the issue and how they are impacted: All populations are impacted.

Challenges:

1. Service infrastructure and design
2. Federal program issues
3. Appropriate targeting of services
4. Role of providers and provider availability
5. Availability of community services and supports
6. Service coordination among institutional and community providers
7. Linkages with other service systems
8. Monitoring and oversight
9. Data/information system issues

Recommendations and rationale for selecting the recommendations:

- QPVIII.1. Change policies to provide additional support to higher education in order to offset high costs of operating health care academic programs.

This would encourage more higher education institutions to provide academic programs to turn out more licensed professionals for this field.

QPVIII.2. Resolve civil liability issues.

This would encourage more individuals to become licensed professionals.

QPVIII.3. Provide for appropriate training and oversight of licensed professionals and facilities, agencies, and programs.

This would ensure quality of service.

QPVIII.4. Reduce paperwork burden and administrative duties of licensed professionals by streamlining regulations and oversight requirements.

This would allow more clinical contact hours with consumers by each licensed professional.

QPVIII.5. Increase opportunities for individuals to receive training, experience, and internships in providing services to persons with disabilities in community setting.

This would encourage professionals to specialize in providing community based services in the disability fields.

QPVIII.6. Increase respect for nursing professionals.

This would increase the number of persons, especially males, in the nursing professions (nursing is seen traditionally as a gender-limited field, thereby impacting its overall profile).

ISSUE IX: TRAINING/TECHNICAL ASSISTANCE

DESCRIPTION OF THE ISSUE: *There is a lack of training and technical assistance for consumers, families and advocates.*

Background and data: Consumer, families, and advocates do not have a consistently available, effective, or accurate way to access technical assistance and information regarding disability rights issues.

Disability populations impacted by the issue and how they are impacted: All populations are impacted.

Challenge:

1. Service infrastructure and design

Recommendations and rationale for selecting the recommendations:

QPIX.1.a. Establish a system to educate consumers, families, and advocates on how the system works, including how to select providers and what their rights are.

QPIX.1.b. Establish a statewide toll-free number that consumers, families, and advocates can contact to ask disability rights questions and be linked with appropriate resources, including technical assistance.

These will ensure that consumers, families, and advocates are well educated, well informed, and able to receive consistent, accurate, information to support their ability to effectively advocate for themselves and receive appropriate supports and services.

G. REPORT OF THE TRANSPORTATION TEAM

Team Chair: Doris Ray

Team Recorder: Barbara Gilley

Agency Convener: Susan Payne, Department of Rehabilitative Services (DRS)

This Team was established mid-way through the Olmstead planning process subsequent to the realization of the Olmstead Steering Committee that issues related to transportation for individuals with disabilities cross all areas of discussion and planning in the development of the Olmstead Interim Report and Olmstead planning activities for the Commonwealth. Membership of this team consists of Steering Committee members representing four existing Issues Teams, including: 1) Educating the Public, Consumers and Families; 2) Employment; 3) Housing; 4) Prevention and Transition; and staff representation from the Department of Rehabilitative Services (DRS) and the Department for the Blind and Visually Impaired (DBVI). Representation from outside of the Steering Committee includes a staff member from Endependence Center of Northern Virginia and individuals from within the Task Force. Membership on this team includes individuals with physical and sensory disabilities. Due to the late development of this Issues Team, representatives from the Department of Rail and Public Transportation (DRPT) were unable to participate in the preparation of the Interim Report, but will be involved in team work relevant to preparation of the final Issues Team report. The Department of Transportation (VDOT) will also be invited to participate in the development of this Team's final report.

Vision and Values:

Transportation is a basic need for all residents of the Commonwealth to support integration into and survival in community living. For individuals with disabilities, transportation is critical. Building upon themes identified in work generated by the Olmstead Issues Teams, the concept exists that individuals with disabilities must be afforded the opportunity to participate in and contribute to work and community living in whatever manner they choose. They must be given equal opportunity to be partners in the planning and development of programs related to improving the lives of individuals with disabilities residing in Virginia, and in raising the consciousness of state and local governing bodies and legislators to the needs specific to individuals with disabilities. Additionally, individuals with disabilities must be involved in all phases of planning for transportation services. In order for individuals with disabilities to take an active role in these and other types of activities related to community living, transportation must be available, affordable, accessible, reliable, and meet the needs of citizens throughout the Commonwealth, including both rural and metropolitan areas.

The Transportation Issue Team's guiding principals are that adequate transportation for people with disabilities, to meet their most basic needs, must be: 1) available, accessible, affordable, and reliable in all regions of the Commonwealth; 2) seamless between transportation modes (for example, air to ground, rail to taxi, and so forth); 3) operational during the same hours as systems used by the general public; 4) safe for all people with disabilities (including transportation infrastructure); and 5) available in emergency situations.

ISSUE I: RELIABLE, ACCESSIBLE TRANSPORTATION INADEQUATE OR LACKING

DESCRIPTION OF THE ISSUE: *There is inadequate or complete lack of reliable, accessible transportation for individuals with disabilities in communities across the Commonwealth of Virginia. Individuals with disabilities are often unable to participate actively in their local communities for the purpose of independent living and work because of unreliable or nonexistent transportation. As well, significant numbers of individuals with disabilities are unable to access transportation because of poverty, and/or a lack of, or inability to develop, driving skills subsequent to functional limitations caused by disability. These barriers, among others such as the need for adaptive equipment, frequently cause dependence on public transportation, which is generally limited to the more metropolitan areas of the Commonwealth. Unfortunately, in the majority of rural communities in Virginia, public transportation is nonexistent. In areas where public transportation is available, hours of operation are limited, and service is inconsistent and unreliable.*

Background and data: There is very limited or no public transportation in many areas of Virginia. Most localities provide the minimum public transportation for the general population; for individuals with disabilities, public paratransit services as required under the Americans with Disabilities Act (ADA) are even scarcer.

Relationship between the issue and current laws, regulations and policies:

State: Virginians with Disabilities Act

Federal:

- **Americans with Disabilities Act:** Non-discrimination against people with disabilities in transportation infrastructure and providers. Public transportation is covered under the ADA, which requires that paratransit be provided within $\frac{3}{4}$ of a mile of public transportation lines. Most localities that provide paratransit provide the minimum required by the ADA.
- **Transportation Equity Act for the 21st Century (TEA-21):** Provides flexibility for state transportation funding on enhancements that lower barriers to people with disabilities. Extends the reach of the Air Carrier Access Act to foreign airlines operating in the United States. It also includes specific provisions for studying lowering of barriers to people with disabilities, such as that concerning insulin-controlled diabetic commercial over-the-road truck drivers.
- **Section 504 of the Rehabilitation Act of 1973, as amended:** Non-discrimination against people with disabilities by recipients of federal financial assistance from DOT.
- **Section 508 of the Rehabilitation Act of 1973, as amended:** Requires electronic information technology accessibility for software and hardware acquired by the federal government.
- **Air Carrier Access Act (ACAA):** Non-discrimination against people with disabilities by commercial passenger airlines.
- **Older Americans Act**
- **Architectural Barriers Act**
- **Titles 19 and 20 of the Social Security Act**
- **Highway Act**

Current programs and initiatives addressing the issue:

1. *Wheelchair securement training* is provided to human service, private, public providers by the Community Transportation Association of Virginia (CTAV) and Community Transportation Association of American (CTAA).
2. *Investigating provider certification:* Providers who meet various criteria are certified to a certain level by CTAV.
3. *ADA compliance:* The Department of Medical Assistance Services (DMAS) requires that all Medicaid transportation providers are ADA compliant.
4. Demonstration funds available to localities to provide transit in rural communities through the *Transit Act*.
5. *Public and Paratransit* through human service transportation programs such as TANF and the Public Mobility Project.

6. Initiatives through *Project Action* provide grant funding for establishment of new transportation services, and use of existing services.
7. *Faith in Action* projects funded by the Robert Woods Johnson Foundation.
8. Initiatives through the *Virginia Board for People with Disabilities*.
9. *Rehabilitation Incentives Funds* through Disability Services Boards.

Disability populations impacted by the issue and how they are impacted: The need of citizens with disabilities residing in Virginia to access transportation to meet basic needs such as going to medical appointments, shopping, going to work, attending school, and otherwise participating in community living and opportunities, crosses disability lines, age groups, and geographic areas. Without a way to physically get from one location to another, individuals with disabilities become isolated, lose the opportunity to work and play in the community with others, and potentially decline in physical and emotional health. People lose their jobs, miss doctors' appointments, go without sundry items, and become increasingly dependent on other people to take care of their most basic needs. Additionally, their family members and providers are frequently confronted with transportation and travel barriers.

Challenges:

1. Lack of adequate and safe curb cuts in parking lots, onto sidewalks, and in and around buildings.
2. Lack of safe evacuation procedures for individuals with disabilities during emergencies.
3. Lack of or adequate transportation of any kind for individuals with disabilities in rural areas throughout the Commonwealth.
4. Gas stations are not equipped to serve individuals with disabilities.
5. Emergency highway call boxes are inaccessible to individuals with disabilities.
6. Traffic calming devices such as speed bumps or tables may be harmful to people with spinal and other orthopedic disabilities or medically fragile conditions.
7. Lack of community understanding of the need for specialized transportation for individuals with disabilities or public transportation generally.
8. Transportation is expensive and requires greater funding privately and on all government levels. The high cost of insurance and specialized equipment and accommodations make the provision of transportation as a service very difficult for providers.

Recommendations and rationale for selecting the recommendations:

- TI.1. Address the lack of transportation for consumers with disabilities by increasing the: a) use of telemedicine; b) provision of services at places convenient to consumers; and c) efficiency and coordination of transportation including sharing of resources by agencies/programs.

Transportation has been identified as a significant barrier to accessing services, and this will increase consumer choice and accessibility and availability of qualified providers.

TI.2. Increase funding and reimbursement for transportation services.

Transportation has been identified as a significant barrier to accessing services, and this will increase consumer choice and accessibility and availability of qualified providers.

TI.3.a. Require providers to be physically accessible to consumers and families and in full compliance with the Americans with Disabilities Act (ADA) and the ADA Accessibility Guidelines (ADAAG) to be considered qualified.

TI.3.b. Require providers to ensure communications access to consumers and families, including providing sign language interpreters, alternate formats and other appropriate communication supports and services in full compliance with the ADA to be considered qualified.

TI.3.c. Require providers to ensure cognitive accessibility so that consumers with cognitive disabilities and their family members and advocates are given the maximum opportunity to understand their rights and make informed choices.

TI.3.d. Require providers to be language accessible by ensuring that non-English speaking consumers are given the maximum opportunity to understand their rights and make informed choices.

These requirements will ensure maximum consumer accessibility and choice.

TI.4. All levels of government, as well as private providers of transportation, should explore possibilities of additional funding to improve transportation for people with disabilities.

ISSUE II: TRANSPORTATION BARRIERS TO COMMUNITY REINTEGRATION

DESCRIPTION OF THE ISSUE: *Individuals with disabilities residing in nursing facilities, state hospitals, and other institutions are unable to access transportation to facilitate their transition from institutionalization to community living. In order to transition out of institutions into the community, individuals with disabilities, especially those unable to drive as a result of functional limitation caused by their disabilities, must have access to appropriate transportation to manage activities associated with setting up housekeeping in a community residence. Prior to discharge, individuals must have transportation to search for housing, make contact with community support agencies or*

entities, set up bank accounts, conduct necessary personal business, shop for furnishings, and coordinate other arrangements to facilitate transition.

Disability populations impacted by the issue and how they are impacted: Any individual with physical, sensory, or cognitive disabilities or impairments residing in institutions who has otherwise been determined to be able to receive adequate and appropriate care in the community and who chooses to transition out of institutions and into the community is potentially impacted by this issue. To establish residence in the community, any number of activities must be undertaken to secure housing, set up telephone, electric, water, sewage, and other public utilities. Individuals with disabilities residing in institutions cannot initiate those services from within the institutional setting. Lack of transportation is often the barrier that prevents transition out of institutions from occurring in a timely manner.

ISSUE III: INACCESSIBLE COMMUNITY INFRASTRUCTURE

DESCRIPTION OF THE ISSUE: *Community infrastructure is not accessible to individuals who require the use of public and paratransit transportation services.*

Challenges:

1. Lack of or inadequate paratransit services. Specific problems include lack of timely service, requirements of next day trip reservations, inadequately trained personnel, and missed calls for pick-ups.
2. Street crossings in both simple and complex intersections are not accessible to pedestrians with sensory, physical, and other types of disabilities and often do not include adequate accessibility features such as availability of, and access to, on-demand crossing buttons and audible signals informing individuals when it is safe to cross.
3. Lack of transportation outside of normal workday hours.
4. Existing public transportation often lacks the appropriate equipment or other accommodations to support individuals with many types of disabilities. Such accommodations include, but are not limited to, safe and appropriate lifts, drivers who are trained to provide assistance to individuals with disabilities getting into or off of the transportation vehicle, providing paper for a means of communications for deaf individuals, and providing audible announcements of transportation stops and other information.

ISSUE IV: INADEQUATE PUBLIC TRANSPORTATION SERVICES

DESCRIPTION OF THE ISSUE: *The inadequacy of public transportation services and resources in communities throughout the Commonwealth severely limits the community living options of persons with disabilities and their families, and frequently*

results in unnecessary institutionalization of individuals lacking the personal and family resources to relocate to a community where better transportation resources exist.

H. REPORT OF THE WAIVERS TEAM

Team Chair: Fred P. Orelove

Team Recorder: Barbara A. Gilley

Agency Convener: Diana Thorpe (DMAS)

The Chair and members of the Waiver Issues Team of the Virginia Olmstead Task Force certify that the membership was representative of and considered the interests of all major disability populations. Members represented the following major disability categories: low vision, hard of hearing, post-polio (physical disabilities), multiple sclerosis, brain injury, developmental disabilities, Alzheimer's/dementia, aging, and mental retardation. In addition, the Team Chair encouraged participation by members of the public throughout each meeting. In addition to some of the categories already listed, public participants represented the major disability categories of HIV/AIDS and Mental Health.

Mission:

The mission of the Waiver Issues Team is to support the work of the Virginia Olmstead Task Force in the development of an effectively working plan that will ensure that Virginians who have disabilities are able to exercise their rights under the Americans With Disabilities Act (ADA) to receive services in the most integrated setting that enables them to live as independently as possible according to their individual needs and preferences. Our focus is to propose changes in Virginia's Medicaid and Medicaid Waiver Programs that support and promote community living.

Guiding Principles:

- 1) Individuals of all ages have the right to live in the communities of their choice.
- 2) The Commonwealth should provide sufficient and adequate supports in the community for elderly individuals and individuals with disabilities.
- 3) All waivers should provide for consumer choice and control.
 - a. Waivers should maximize capacity for consumer direction, and
 - b. Services should be tailored to the needs and preferences of the individual.
- 4) Services must be affordable, accessible, available, reliable and accountable.

ISSUE I: RIGHTS

DESCRIPTION OF THE ISSUE: *Rights of individuals with disabilities regarding waivers and waiver services are not universally upheld.*

Background and data: Consumers often are not informed of their rights, and providers, who should be informing consumers, frequently are not knowledgeable about those rights. The right of choice is often inappropriately limited.

Current programs and initiatives addressing the issue:

An *Independence Plus Waiver* for persons with mental retardation and developmental disabilities, using a new federal template, has been proposed, and a work group convened by DMAS is meeting to work out the details.

Disability populations impacted by the issue and how they are impacted: All populations are impacted by this issue.

Challenges:

1. Service infrastructure and design: Training materials for consumers and providers are inadequate, and no training is universally conducted.
2. Monitoring and oversight: There is inadequate monitoring and oversight around providing information to consumers.

Recommendations and rationale for selecting the recommendations:

- WI.1.a. DMAS should produce and distribute a document regarding rights and choices for all waiver services.
- WI.1.b. Training on rights and choices for all waiver services should be developed and delivered to individuals and providers.
- WI.2. DMAS should include language in utilization review and quality assurance to determine the effective distribution, understanding, and implementation of training and related materials.

ISSUE II: FINANCIAL ELIGIBILITY FOR MEDICAID

DESCRIPTION OF THE ISSUE: *Basic needs to support independent living in the community are not being met because of overly restrictive financial eligibility for Medicaid.*

Background and data: Virginia's criteria for Medicaid financial eligibility was recently raised to 80% of the Federal Poverty Level, well below the national average of 120% of the Federal Poverty Level.

Disability populations impacted by the issue and how they are impacted: All populations are impacted by this issue.

Challenges:

1. Service infrastructure and design: Insufficient funds have been allocated to pay for an increased financial eligibility level.
2. Availability of community services and supports: Current financial eligibility level limits access to these services and supports by those who could not otherwise afford them.

Recommendation and rationale for selecting the recommendation:

- WII.1. DMAS should increase the Medicaid financial eligibility by using, at a minimum, the national average of the Federal Poverty Level, and the General Assembly should appropriate additional funds to pay for it.

ISSUE III: ELIGIBILITY CRITERIA FOR LONG-TERM CARE

DESCRIPTION OF THE ISSUE: *Basic needs to support independent living in the community are not being met with current waivers because of Virginia's overly restrictive level of care eligibility criteria for long-term care services.*

Background and data: Virginia has set much more restrictive level of care criteria for long-term care services than many other states. Many individuals in Virginia with disabilities are not eligible for the existing waivers. With appropriate community services, many of these individuals could remain in their own homes in the community.

Disability populations impacted by the issue and how they are impacted: All populations are impacted by this issue.

Challenges:

1. Service infrastructure and design: Virginia's more restrictive eligibility criteria limit access to supports needed to live in the community.
2. Appropriate targeting of services: Overly restrictive eligibility criteria limit Virginia's ability to maximize resources.

Recommendations and rationale for selecting the recommendations:

- WIII.1. a. DMAS, with authorization from the General Assembly, should
and 2. redefine level of care eligibility for long-term care services.

- WIII.1.b. DMAS, with authorization from the General Assembly, should institute a program of regular and on-going training for screening personnel.

ISSUE IV: ARRAY OF WAIVER SERVICES

DESCRIPTION OF THE ISSUE: *Basic needs to support independent living in the community are not being met with current waivers because there is not a sufficient array of Waiver services.*

Background and data: Virginia has established arbitrary limits on the amount and scope of services. In doing so, Virginia is not using the latitude available under the federal 1915(c) waiver program. In addition, other important services are not included in all waivers. Licensure is too restrictive and limits consumer direction of services.

Current programs and initiatives addressing the issue:

1. An *Independence Plus Waiver* for persons with mental retardation and developmental disabilities, using a new federal template, has been proposed, and a work group convened by DMAS is meeting to work out the details.
2. *Expansion of consumer directed services:*
 - *AIDS Waiver* will add consumer-directed attendant care.
 - *DD Waiver* will offer consumer-directed companion care.
 - *CD PAS Waiver* will be amended to allow other individuals to direct care on behalf of the waiver recipient.

These waivers are administered by DMAS.

Disability populations impacted by the issue and how they are impacted: All populations are impacted by this issue.

Challenges:

1. Service infrastructure and design: Insufficient funds are appropriated to allow DMAS to provide amount, scope, and types of services individuals need. Allocation of funds in Virginia is not based on individuals' needs and choices.
2. Role of providers and provider availability
3. Availability of community services and supports

Recommendations and rationale for selecting the recommendations:

- WIV.1.a. DMAS should amend waivers to include, but not be limited, to (1) addition of consumer directed services to all of the waivers; (2) a provision for personal care providers to be reimbursed for room and board or provision for a night rate in those instances where the individual does not require a live-in attendant; (3) expansion of awake overnight

reimbursed care to 8 hours; and (4) addition of a service of behavioral support.

- WIV.1.b. DMAS should amend all waivers to include concepts and options including, but not limited to, the Independence Plus waiver template.
- WIV.2. Licensing entities, in conjunction with DMAS and other interested parties, should amend licensing requirements to allow consumer direction of all waiver services.
- WIV.3. The General Assembly should appropriate additional funds to expand Medicaid State Plan Option services to include Personal Assistance services with an option for consumer direction.

ISSUE V: INDIVIDUALS WITH MENTAL ILLNESS

DESCRIPTION OF THE ISSUE: *People with mental illness are not receiving the services they need to avoid homelessness or institutionalization.*

Background and data: Over 80% of homeless people living on the streets have mental illness and/or a co-occurring substance addiction. Options for people with mental illness need to be expanded.

Disability populations impacted by the issue and how they are impacted: People living with mental illness and/or a co-occurring substance addiction are impacted by this issue. They are not receiving the services they need to avoid homelessness or institutionalization.

Challenges:

1. Service infrastructure and design: A waiver and corresponding funding do not exist to address the needs of individuals with mental illness and/or co-occurring substance addictions.
2. Availability of community services and supports: A waiver and corresponding funding do not exist to address the needs of individuals with mental illness and/or co-occurring substance addictions.

Recommendations and rationale for selecting the recommendations:

WV.1.a. Expand availability of crisis stabilization programs.

No less restrictive alternative is available to avert costly hospitalization.

WV.1.b. Expand-street outreach and Programs of Assertive Community Treatment (PACT) teams to engage homeless and hard to reach individuals with mental illness.

Fragile individuals with mental illness require intensive and ongoing supports to become stabilized and maintain housing.

WV.1.c. Expand affordable housing alternatives and rent subsidy programs.

Individuals with mental illnesses often subsist on social security and cannot afford available housing options at fair market rents.

WV.2.a. The General Assembly should enable people with serious mental illness and serious emotional disturbance to receive state funded core services (i.e., case management, home based services, residential services, psychiatry, medical, and rehabilitation programs).

WV.2.b. The General Assembly should add bundled Programs of Assertive Community Treatment (PACT) services to the Medicaid State Plan Option.

WV.2.c. The General Assembly should expand the service array that is reimbursable via the Medicaid State Plan Option to include Programs of Assertive Community Treatment (PACT), expanded residential supports, personal assistance, and consumer-run services.

These would serve to reduce the use of more costly services by front-end supports and services; reduce human misery, deaths, and institutionalization; and maximize resources.

ISSUE VI: TRANSITIONAL FUNDING

DESCRIPTION OF THE ISSUE: *Lack of transitional funding creates a barrier for people moving to the living arrangement of their choice.*

Background and data: Virginia has not elected to take advantage of new federal policy that would allow the use of Medicaid waiver funds to support an individual's transition from institutions to their own homes or apartments in the community. This recommendation suggests adopting a measure similar to Rider 37 by which the Texas legislature authorized funding for Transition/Diversion.

Current programs and initiatives addressing the issue:

1. *Texas Rider 37*, which authorizes funding for a transition/ diversion program (Texas Legislature).
2. *Massachusetts Personal Care Option*, a Medicaid State Plan Option that includes

transition services (Massachusetts Legislature).

Disability populations impacted by the issue and how they are impacted: All populations are impacted by this issue.

Challenge:

1. Service infrastructure and design: Allocation of funds is not based on individuals' needs and choices.

Recommendation and rationale for selecting the recommendation:

- WVI.1. DMAS should amend waivers and/or amend state plan options to include transition funds and secure General Assembly funding to cover those costs.

ISSUE VII: WAIVER RATES

DESCRIPTION OF THE ISSUE: *Inadequate Medicaid Waiver payment rates limit access to services and choice of providers by consumers.*

Background and data: Low payment rates reduce the supply of providers, which limits access and choice. Few providers are willing to take consumers with challenging behaviors or intensive medical needs. Some providers are discharging these individuals because they cannot meet their health and safety needs. Providers are closing homes due to the high cost of doing business in certain parts of the state.

Disability populations impacted by the issue and how they are impacted: All populations are impacted by this issue.

Challenge:

1. Availability of community services and supports: All six of the existing waivers are affected by low payment rates. With payment rates that are not commensurate with the cost of providing services, providers are reluctant to take on new consumers and are unable to offer certain waiver services. With a declining provider base, choice of providers is often non-existent.

Recommendation and rationale for selecting the recommendation:

- WVII.1. The General Assembly should appropriate, and DMAS should target, funds to (a) increase rates to cover cost of service; (b) include automatic COLAs; (c) include geographical rate differentials; (d) reimburse travel; and (e) ensure that rate increases are reflected in caregiver pay rates.

Inadequate rates severely limit the choice of providers, which could be a violation of Medicaid law.

ISSUE VIII: WAIVER CAPS

DESCRIPTION OF THE ISSUE: *Existing waivers have arbitrary caps and limits on funds based on cost rather than individual need.*

Background and data: Virginia waivers use arbitrary caps and limits that prohibit individuals with the most severe disabilities from receiving services needed to live independently in their communities. In large part, these service caps are the result of Virginia's utilization of individual caps in its cost neutrality calculation for waivers rather than using aggregate cost methods. In addition, individuals with the most severe disabilities are unable to access the choice of the consumer directed option.

Disability populations impacted by the issue and how they are impacted: All populations are impacted by this issue.

Challenge:

1. Availability of community services and supports

Recommendation and rationale for selecting the recommendation:

- WVIII.1. DMAS should cost all waivers using the Aggregate Cost methodology and eliminate service hour thresholds for personal assistance and skilled nursing.

ISSUE IX: MEDICAL NEEDS

DESCRIPTION OF THE ISSUE: *People currently living in institutional facilities cannot obtain appropriate, adequate and sufficient services to meet their medical needs through the current waivers in order to live in the community.*

Background and data: The average cost of services provided through the Tech Waiver is \$85,553. Many people residing in institutional facilities could reside in the community, but their plans of care would approach or exceed the artificially low Medicaid payment rates for facilities.

Disability populations impacted by the issue and how they are impacted: All populations are impacted by this issue.

Challenges:

1. Availability of community services and supports: Artificially low payment rates to facilities result in low cost neutrality measure for waivers. These low rates also have an adverse impact on people with disabilities accessing services in the community through the CD-PAS and Tech Waivers.
2. Service infrastructure and design

Recommendations and rationale for selecting the recommendations:

WIX.1.a. DMAS should use the Aggregate Cost methodology for the CD-PAS and 2. and Tech Waivers so that plans of care can approach or exceed the current Medicaid payment rates for institutions.

WIX.1.b. The General Assembly should increase the Medicaid payment rate to nursing facilities to no less than 100% of the Medicaid allowable cost.

More people could live in the community if DMAS would approve more expensive Waiver plans of care.

ISSUE X: HEALTH AND SAFETY

DESCRIPTION OF THE ISSUE: *People with disabilities do not have reliable Waiver services in order to ensure the individual's health and safety in the community.*

Background and data: Virginia's waiver regulations for back-up and substitute services are not consistently being enforced.

Current programs and initiatives addressing the issue:

1. *Greater Independence and Mobility Project (GIMP)*, an on-call backup initiative, privately operated.

Disability populations impacted by the issue and how they are impacted: All populations are impacted by this issue.

Challenge:

1. Monitoring and oversight

Recommendation and rationale for selecting the recommendation:

WX.1. DMAS should enforce regulations for agency backup and work to increase payment rates.

ISSUE XI: HOUSING CHOICE

DESCRIPTION OF THE ISSUE: *Waiver regulations and policies unfairly restrict choice in housing.*

Background and data: Waiver regulations and policies currently prohibit consumers who live together from pooling Personal Assistance hours. In addition, the DD Waiver specifically prohibits more than two unrelated individuals living in the same household from receiving Waiver services.

Disability populations impacted by the issue and how they are impacted: All populations are impacted by this issue.

Challenges:

1. Service infrastructure and design
2. Availability of community services and supports

Recommendations and rationale for selecting the recommendations:

- WXI.1.a. Individuals should be assessed for the number of hours they need on an individual basis.
- WXI.1.b. Individuals should be allowed to make their own personal choices regarding who, and how many people, they live with.
- WXI.2. DMAS should amend its regulations and policies in order to authorize the amount of Waiver services that are needed on an individual basis.

Individuals are being penalized by DMAS policies for pursuing living arrangements that clearly fall within the purview of individual choice and preference.

ISSUE XII: NURSE PRACTICES ACT

DESCRIPTION OF THE ISSUE: *The current nurse delegation requirement of the Nurse Practices Act limits the implementation of consumer directed services in Virginia.*

Background and data: The requirement for nurse supervision is too stringent.

Disability populations impacted by the issue and how they are impacted: All populations are impacted by this issue.

Challenge:

1. Linkages with other service systems

Recommendations and rationale for selecting the recommendations:

- WXII.1. The General Assembly should amend the Nurse Practices Act to exclude personal assistants, respite workers, and companion aides, under the direction of a consumer or his or her surrogate from the delegation requirements of the Act. (Compare language from Kansas Statute 65-1124(1) & associated statutory language)

ISSUE XIII: PERSONAL MAINTENANCE ALLOWANCE

DESCRIPTION OF THE ISSUE: *The Personal Maintenance Allowance (PMA) is not equitable across Waivers and is insufficient under some Waivers to allow community living.*

Background and data: Individuals are unable to pay the required co-pay and meet their personal expenses for shelter, food, and clothing in order to live in the community.

Disability populations impacted by the issue and how they are impacted: All populations are impacted by this issue.

Challenge:

1. Availability of community services and supports

Recommendation and rationale for selecting the recommendation:

- WXIII.1. The General Assembly should increase the PMA to 300% of the monthly SSI payment limit in all waivers.

ISSUE XIV: NEEDS ASSESSMENT DATA

DESCRIPTION OF THE ISSUE: *No reliable system exists for capturing needs assessment data for consumers with developmental, physical, and sensory disabilities.*

Background and data: Without credible data, the General Assembly cannot know how much money is needed to prevent institutionalization. Staff and members of the General Assembly must be able to accurately assess the fiscal liability for unmet service needs for all disabilities, not just mental disabilities.

Current programs and initiatives addressing the issue: Disability Service Boards are mandated by state law to collect needs data for people with physical and sensory disabilities, but there is no responsible entity.

Disability populations impacted by the issue and how they are impacted: The Department of Mental Health, Mental Retardation, and Substance Abuse Services (DMHMRSAS) biennially prepares a six-year Comprehensive State Plan for individuals with mental retardation, mental illness, and substance abuse disorders which is mandated by state code to be used in the Department's annual budget submission to the Governor. This plan entails a public hearing process and identifies the number of individuals who will eventually need services. This comprehensive data collection is not currently performed for consumers with developmental or physical disabilities and there is no meaningful way to plan for the "unmet" need without these data.

Challenge:

1. Data/information system issues

Recommendation and rationale for selecting the recommendation:

- WXIV.1. The General Assembly should direct and adequately fund the Statewide Independent Living Council to conduct a periodic Comprehensive State Plan for people with physical, sensory, and developmental disabilities. This should include a census of persons in institutional settings needing and wanting to transition to the community, and require that budget submissions to the Governor be based on these data.

DMHMRSAS performs this function for individuals with mental disabilities. A determination of the unmet needs should be performed periodically for all disabilities.

**ISSUE XV: REPORTING OF CRITICAL INCIDENTS AND DEATHS
IN WAIVER PROGRAMS**

DESCRIPTION OF THE ISSUE: *Critical incidents (i.e., serious bodily injuries) and deaths are not required to be reported to the Virginia Office for Protection and Advocacy for individuals receiving Waiver services.*

Background and data: Critical incidents and deaths that occur within state facilities operated by the Department of Mental Health, Mental Retardation, and Substance Abuse Services (DMHMRSAS) are required by law to be forwarded to the Virginia Office for Protection and Advocacy (VOPA) in an expedient manner. There is not a similar requirement for critical incidents and deaths that occur in community-based programs. According to an internal DMAS document, Opportunities for Independent Living, only the CD PAS regulations contain reporting requirements for critical incidents. Since other state licensing agencies have regulations that require timely reporting, there is an absence of uniform requirements.

Relationship between the issue and current laws, regulations and policies: The DMHMRSAS state facilities are required to report critical incidents and deaths to VOPA

under Va. Code §§ 37.1-42.1, 37.1-42.2, and 51.5-39.12. Currently, DMHMRSAS-licensed Waiver programs are required under DMHMRSAS licensing regulations to report serious injuries and deaths to DMHMRSAS within 24 hours. Within DMHMRSAS, there is also an extensive human rights regulatory process.

Current programs and initiatives addressing the issue:

1. *DMHMRSAS Licensing Program*
2. *DMHMRSAS Human Rights Program*

Disability populations impacted by the issue and how they are impacted: All populations receiving Waiver services are impacted by this issue.

Challenge:

1. Monitoring and oversight

Recommendation and rationale for selecting the recommendation:

WXV.1. DMAS should amend all Waiver regulations to require that critical incidents and deaths be forwarded to VOPA within 48 hours. The General Assembly should appropriate funds to allow VOPA to analyze the data for trends.

Assuring the health and safety of individuals living in the community is a critical responsibility of government.

ISSUE XVI: MR AND DD WAIVER WAITING LISTS

DESCRIPTION OF THE ISSUE: *Wait lists for the MR and DD Waivers move at an imperceptible pace and are a barrier to receiving appropriate services in a timely manner.*

Background and data: There are over 5,500 individuals currently served on the MR Waiver, and the wait list for MR Waiver slots exceeds 2,300. There are more than 800 individuals with mental retardation who DMAS has listed on their Urgent Wait List as requiring services within 90 days. There are 325 individuals currently served on the DD Waiver, but the wait list for DD Waiver slots exceeds 372. By virtue of being on a wait list for the MR or DD Waiver, an individual has met the criteria for an ICF/MR level of care. If consumers are eligible for services and have an immediate need for services, but are not receiving services, they face institutionalization.

Disability populations impacted by the issue and how they are impacted: Individuals served by the MR and DD waivers. People who have met the eligibility criteria for the MR and DD Waivers are either not receiving the services for which they are eligible, or

are receiving the services with 100% state General Fund dollars, tying up resources that could be used to reduce the wait list.

Challenge:

1. Availability of community services and supports

Recommendation and rationale for selecting the recommendation:

WXVI.1. The General Assembly should appropriate additional funds each year to meet the needs of the Urgent Wait Lists and incrementally eliminate the entire wait list.

This needs to be done because wait lists that do not move at a “reasonable” pace are a violation of the Olmstead decision.

ISSUE XVII: INDIVIDUALS WITH DEMENTIA

DESCRIPTION OF THE ISSUE: *People with dementia need community options to avoid institutional placement.*

Background and data: People with dementia are at high risk for institutional placement but do not currently receive targeted assistance to remain in the community.

Disability populations impacted by the issue and how they are impacted: Individuals with dementia, regardless of the cause. People with dementia are at high risk of institutional placement and do not currently receive targeted assistance to live in the community.

Challenges:

1. Service infrastructure and design: A waiver and corresponding funding do not exist to address the needs of individuals with dementia.
2. Role of providers and provider availability: There is a limited availability of rural providers.
3. Availability of community services and supports: There is a limited availability of rural community services and supports.

Recommendations and rationale for selecting the recommendations:

WXVII.1. DMAS should develop a Dementia Waiver, and the General Assembly should appropriate funding for this Waiver.

People with dementia are at high risk for institutional placement.

ISSUE XVIII: INDIVIDUALS WITH BRAIN INJURIES

DESCRIPTION OF THE ISSUE: *People who have sustained disabling brain injuries need community options to avoid institutional placement.*

Background and data: People with brain injuries are at high risk for institutional placement, but currently do not receive assistance to remain in the community.

Disability populations impacted by the issue and how they are impacted: Individuals with brain injuries. Without a Waiver, no mechanism exists to provide services to people with brain injury to allow them to live in the community or to avoid institutional placement.

Challenges:

1. Service infrastructure and design: Appropriate services--in particular neurobehavioral services--do not exist in Virginia.
2. Federal program issues
3. Appropriate targeting of services: Specific services are required to address the unique needs of individuals with brain injury.
4. Role of providers and provider availability: A funding stream is required to develop providers.
5. Availability of community services and supports: A funding stream is required to develop community services and supports.

Options:

WOpXVIII.1. Approval of brain injury waiver.

Recommendations and rationale for selecting the recommendations:

WXVIII.1. DMAS should develop a Brain Injury Waiver, and the General Assembly should appropriate funding for this Waiver.

People with brain injuries are at high risk for institutional placement.

***TASK FORCE WORKPLAN
REVISED: MARCH 26, 2003***

2002:

- 7/31 Hold 1st Task Force meeting:
- ❖ Orientation to the Olmstead case and charge of Task Force
 - ❖ Education re: the national Olmstead scene
 - ❖ General approach to Task Force work, including steering committee
 - ❖ Discuss populations/services processes
 - ❖ Identify issues and form issues teams
- Mid-August Convene issues teams —select chairs and recorders; begin work
- By late August Convene initial steering committee meeting
- Mid-September Hold 2nd Task Force meeting:
- ❖ Presentations from state that has written an “Olmstead” plan
 - ❖ Reports to task force re: issues teams plans and progress
 - ❖ Discussion of reports
 - ❖ Review draft status report to JCHC
- Issues teams continue to meet
Agencies initiate processes for obtaining population and service information
- By 9/30 Submit initial written status report to JCHC, with copy to Disabilities Commission
- 10/01 to 11/15 Issues teams continue to meet
Agency populations/services processes continue
- By 11/15 Hold 3rd Task Force meeting:
- ❖ Public comment period
 - ❖ Reports from issues teams and agencies
 - ❖ Discussion of reports
 - ❖ Review draft presentation to JCHC
- Issues teams continue to meet as needed
Agency populations/services processes continue as needed
- By 11/30 Presentation to JCHC; copy of presentation to Disabilities Commission

2003:

- 1/1/03 Finalize Consumer Feedback Form
- 1/1/ to 3/31 Issues Teams continue to meet as needed
Populations/services processes continue as needed
- 1/7/03 Hold 4th Task Force Meeting
❖ Review and discuss issues being identified by Teams
- 1/15/03 Send out Facility/Residential Services Survey
- 2/28/03 Reports due from Issues Teams
- 3/7/03 Steering Committee meets to finalize Draft Interim Task Force Report
- 3/26/03 Hold 5th Task Force meeting:
❖ Action on Draft Interim Task Force Report
❖ Review JCHC presentation
- 4/1 to 5/31 Issues teams continue to meet as needed
Populations/services processes continue as needed
- By 4/15 Final Interim Task Force Report distributed for public comment
- 5/9 Agency Populations and Services Reports due
- By 5/31 Steering Committee meets to consider public comment on Final Interim Task Force Report, recommend implementation strategies, priorities and time frames

Final presentation to JCHC; copy of presentation to Disabilities Commission

Issues teams continue to meet as needed
Populations/services processes continue as needed
- 6/9/03 Hold 6th Task Force meeting:
❖ Public comment period
❖ Consideration of recommended implementation strategies, priorities and time frames
❖ Review proposed report to JCHC
- By 6/20 Final Draft Task Force Report distributed for public comment

Submit draft report to Task Force members and agencies for review and comment by 7/18/03
- 7/28/03 Hold 7th and Final Task Force meeting
❖ Act on Final Task Force Report
- By 8/31/03 Submit final report to Governor, JCHC, Committee Chairs
- By 9/30/03 Present final report to JCHC

MEMBERS OF THE TASK FORCE**APPENDIX B**

First Name	Last Name	Organization Name
Ms. Seville	Allen	Department for the Blind and Vision Impaired
Ms. Jane B.	Anthony	Parents & Associates of the Institutionalized Retarded
Ms. Janet	Areson	Virginia Municipal League
Ms. Mary Lynne	Bailey	Virginia Health Care Association
Ms. Linda	Broady-Myers	Old Dominion Council of the Blind and National Industries for the Blind
Mr. Charles S.	Brown	National Federation of the Blind of Virginia
Mr. Michael	Cooper	VA Association of Centers for Independent Living
Ms. Margaret N.	Crowe	Voices for Virginia's Children
Ms. Ann	Cutshall	Virginia Association for the Deaf and Blind
Mr. Gerald E.	Deans	Department of Mental Health, Mental Retardation and Substance Abuse Services
The Honorable Jeannemarie	Devolites	<i>Ex officio</i> , House of Delegates
Ms. Cora	Dickerson	Richmond Disability Services Board (5th District)
Ms. Grace	DiLiberto, Esq.	Virginia Department of Health
Ms. Elin C.	Doval	Virginia Board for People with Disabilities
Mr. William J.	Ernst, III	Department of Housing & Community Development
Anita	Everett, M.D.	Office of the Inspector General
Mr. Mike	Farley	Virginia Coalition of Private Provider Assocs.
Ms. Jennifer G.	Fidura	Virginia Network of Private Providers
Ms. Vicky M.	Fisher, MS, RN, CS	Mental Health Association of Virginia
Mr. Andrew	Friedman	VA Association of Housing & Community Development Officials
Mr. Carey	Friedman	Office of Lieutenant Governor, Commonwealth of Virginia
Mr. William E.	Fuller	Housing Opportunities Made Economical (H.O.M.E.)
Mr. Grant	Goldman	Virginia Adult Home Association
Ms. Nita	Grignol	Virginia Association of Community Services Boards
The Honorable Frank	Hall	<i>Ex officio</i> , House of Delegates
The Honorable Phil	Hamilton	<i>Ex officio</i> , House of Delegates
Ms. Maureen	Hollowell	Developmental Disabilities Advisory Council
The Honorable Janet	Howell	<i>Ex officio</i> , Senate of Virginia
Ms. Leslie	Hutcheson-Prince	Department for the Deaf & Hard of Hearing
Ms. Lynette	Isbell	Department of Social Services
Ms. April	Kees	Joint Commission on Health Care
Mr. Ian	Kremer, J.D.	Alzheimer's Association
Ms. Joyce	Kube	VA Interfaith Committee on Mental Illness Ministry and Parents and Children Coping Together
Ms. Joani	Latimer	Office of the State Long-Term Care Ombudsman
Ms. Katherine W.	Lawson	Virginia Board for People with Disabilities
Ms. Val	Marsh	NAMI-VA
Mr. Jonathan	Martinis	Virginia Office for Protection and Advocacy
Dr. Mary	Mehaffey	VA Council of Administrators of Special Education

Mr. Barry	Merchant	Virginia Housing Development Authority
Ms. Karen	Michalski-Karney	Virginia Statewide Independent Living Council
Mr. Robert	Mitchell	PAIMI Council
Ms. Paige C.	Moore	Virginia Spinal Cord Injury Council
Dr. Fred	Orelove	Partnership for People with Disabilities
The Honorable Russell	Potts	<i>Ex officio</i> , Senate of Virginia
Ms. Susan D.	Payne	Department of Rehabilitative Services
Dr. Lissa	Power-deFur	Department of Education
Ms. Martha	Pulley	Virginia Association of Home Care
Ms. E. Janet	Riddick	Department for the Aging
Mr. David	Sadowski	Virginia Coalition for the Aging
Mr. Alan G.	Saunders	Office of Comprehensive Services
Ms. Carol	Schall	Virginia Autism Resource Center
Mr. Michael	Scione	Virginia Assistive Technology Loan Fund Authority
Ms. Teja S.	Stokes	The Arc of Virginia
Ms. Karen	Tefelski	VA Association of Community Rehabilitation Programs
Ms. Marcia	Tetterton	VA Association of Nonprofit Homes for the Aging
Ms. Diana	Thorpe	Department of Medical Assistance Services
Mr. John	Toscano	The Autism Program of Virginia (TAP-VA)
Ms. Alice	Tousignant	Virginia Supportive Housing
Mr. J. Thomas	Treece	Substance Abuse & Addiction Recovery Alliance
Ms. Susan	Umidi	Virginia League of Social Service Executives
Ms. Claire	Velzy	Virginia Guardianship Association
Ms. Susan	Ward	Virginia Hospitals & Healthcare Association
Mr. Harry	Weinstock	Brain Injury Association of Virginia
Ms. Roxanne	White	Virginia Association of Counties
Mr. Steve	Williams	Virginia Association of the Deaf
Mr. David	Williams	Virginia Rehabilitation Association
The Honorable Jane H.	Woods	Commonwealth of Virginia
Mr. David	Young	People First

State agencies serving on and providing assistance to the Task Force:

- Board for People with Disabilities (BPD)
- Department for the Aging (VDA)
- Department for the Blind and Vision Impaired (DBVI)
- Department for the Deaf and Hard of Hearing (DDHH)
- Department of Education (DOE)
- Department of Health (VDH)
- Department of Housing and Community Development (DHCD)
- Department of Medical Assistance Services (DMAS)
- Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS), Coordinator

- Department of Rehabilitative Services (DRS)
- Department of Social Services (DSS)
- Office of Comprehensive Services (OCS)
- Virginia Assistive Technology Loan Fund Authority (VATLFA)
- Virginia Housing Development Authority (VHDA)
- Virginia Office for Protection and Advocacy (VOPA)

ISSUES TEAMS**APPENDEX C**

ISSUES TEAM	CHAIRPERSON	RECORDER	AGENCY CONVENER	MEMBERS	MEETINGS
Accountability	E. W. Cline, Jr.	Kate Gaston	VOPA	Seville Allen Jane Anthony Janet Areson Pat Bennett Martha Bryant Wally Cline Michael Cooper Dr. Anita Everett Vicky Fisher LaRa Gibson Jonathan Martinis Marilyn Riddle Carol Schall Karen Tefelski J. Thomas Treece Susan Ward Roxanne White	September 3, 2002 October 1, 2002 November 4, 2002 December 12, 2002 January 9, 2003 February 3, 2003
Educating the Public, Consumers and Families	Janet Bixby Ann Cutshall	Stacey Atwell	DMHMRSAS	Stacey Atwell Jean Beale Sonny Beale Pat Bennett Janet Bixby Linda Broady-Myers Martha Bryant Ann Cutshall Jennifer Edwards-Englestead Stacie Fisher Vicky Fisher Carter Harrison Dr. Anne Kisor Dr. Paula Kupstas Martha Lambert Joani Latimer Katherine W. Lawson Martha Pulley Marilyn Riddle David Sadowski Alan Saunders Ann B. Smith Dr. David Suttle Margaret Walsh Rev. L. William Yolton	August 29, 2002 October 31, 2002 November 20, 2002 December 18, 2002 January 3, 2003 February 12, 2003

Employment	Karen Tefelski	Susan Payne Karen Tefelski	DRS	Mark Baker Elin Doval Michael Farley Lynette Isbell Susan O'Mara Susan Payne Ramont Reed Wanda Rue Michael Scione Karen Tefelski Ed Turner Alan Wooten	September 16, 2002 October 10, 2002 November 15, 2002 December 13, 2002 January 10, 2003 February 7, 2003
Housing	Barbara Gilley	Bill Ernst	VHDA VHCD	Cora Dickerson Bill Ernst Andrew Friedman William Fuller Barbara Gilley Grant Goldman Barry Merchant Alice Tousignant	September 6, 2002 October 18, 2002 November 13, 2002 November 25, 2002 December 9, 2002 December 30, 2002 February 10, 2003 February 24, 2003
Prevention and Transition Services	Ian Kremer		DMHMRSAS	Jane Anthony Margaret Crowe Jerry Deans Helga Fallis Vicki Fisher Nita Grignol Ian Kremer Joyce Kube Valerie Marsh Karen Michalski- Karney Mike Savory Teja Stokes Claire Velzy William Ward Harry Weinstock	September 5, 2002 October 21, 2002 November 18, 2002 December 16, 2002 January 6, 2003 January 24, 2003 February 24, 2003
Qualified Providers	John Toscano	Steve Waldron Karen Tefelski	VOPA	Charles Brown Leslie Hutcheson- Prince Jonathan Martinis Paige Moore Dr. Lissa Power- deFur Karen Tefelski John Toscano Susan Umidi	September 4, 2002 October 11, 2002 November 5, 2002 December 3, 2002 January 6, 2003 January 24, 2003 February 5, 2003

Transportation	Doris Ray	Barbara Gilley	DRS	Seville Allen Janet Bixby Bill Fuller Darrell Feasel Barbara Gilley Susan Payne Karen Tefelski	March 31, 2003
Waivers	Fred Orelove	Barbara Gilley	DMAS	Mary Lynn Bailey Raymond Burmester Jackie Crews Jennifer Fidura Carey Friedman Barbara Gilley Nita Grignol Maureen Hollowell Fred Orelove Doris Ray Janet Riddick Teja Stokes Marcia Tetterton Diana Thorpe Harry Weinstock David Williams	October 2, 2002 October 17, 2002 November 1, 2002 November 26, 2002 January 10, 2003 February 27, 2003