



Biennial Assessment *of the*

Disability Services System
in Virginia



VIRGINIA BOARD FOR PEOPLE
WITH DISABILITIES

Virginia's Developmental Disabilities Planning Council

April 2006

**This excerpt of the full report
has been prepared for the meeting of the
Virginia Disability Commission
on
June 20, 2006.**

**Biennial Assessment
of the Disability Services System in Virginia**

May 1, 2006

This report is also available in alternative formats and on the Virginia Board's website.
For more information, please contact the Board at:

VIRGINIA BOARD FOR PEOPLE WITH DISABILITIES

Ninth Street Office Building
202 North 9th Street, 9th Floor
Richmond, Virginia 23219

804-786-0016 (voice & TTY)
800-846-4464 (toll-free, voice & TTY)
804-786-1118 (fax)

info@vbpd.virginia.gov
www.vaboard.org

This publication was prepared with 100% federal funding
under the Developmental Disabilities and Bill of Rights Act.

I. Executive Summary

The Virginia Board for People with Disabilities (hereafter referred to as the Board), Virginia's Developmental Disabilities (DD) Planning Council, is pleased to provide its **2006 Biennial Assessment of Virginia's Disability Services System**. This Assessment was produced in accordance with the Code of Virginia (§51.5-33 [2]) and the federal Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402, 2000).

Background: Federal and state legislation direct the Board to engage in advocacy, capacity building, and systems change activities working with and on behalf of individuals with developmental disabilities and their families. The Board engages in an array of diverse activities including, but not limited to: outreach and training, educating communities, building coalitions, helping to guide public policy. As the Commonwealth's DD Planning Council, the Board represents an independent voice and a source of information on and knowledge of many issues affecting its constituents. The Board's work on behalf of Virginia's citizens is enhanced by the diversity of its membership, which includes persons with disabilities, family members, advocates, state and local government officials, service providers, and representatives of various private sector interests.

Over the past two decades, the Board has provided millions of dollars of federal funding and has leveraged significant amounts of additional local government and private-sector funding to promote the demonstration, implementation, and replication of policies, programs, and practices designed to move the service system in a forward direction. However, the Board's current funding level (approximately \$1.5 million per year) can only touch the surface of the complex issues facing the Commonwealth in its efforts to ensure full inclusion and quality of life for its citizens with developmental and other disabilities.

The purpose of the Board's Biennial Assessment function is to provide an ongoing, reliable mechanism to evaluate, report on, and make recommendations regarding the effectiveness of the service delivery system in meeting the current and future needs of persons with developmental and other disabilities. It is critical for Virginia to identify the most pressing service needs and to develop innovative and cost effective ways to meet these needs in ways that respect human and civil rights and uphold the dignity of persons with disabilities.

Issues and Trends: The Commonwealth has made many positive strides in the area of disability services within the last few years. Two Governors have issued consecutive Executive Orders directing implementation of the U.S. Supreme Court's *Olmstead v. L.C.* decision, reflecting an important commitment to community integration for persons with disabilities. Additional funding has been provided for autism and brain injury services and the Commonwealth's Centers for Independent Living. The 2005 General Assembly approved the addition of 860 waiver "slots" to the MR Home and Community Based Medicaid Waiver and 105 funded slots were added to the Developmental Disability (DD) Waiver. At the time of this report, a budget request for funding of additional Waiver slots for both the MR and DD Waivers was pending in the 2006 General Assembly. In July 2005, the Elderly and Disabled and Consumer Directed Personal Assistance Services Waivers were merged; this allows for consumer direction of all services

under the “new” waiver. An Alzheimer’s Waiver has been developed and a Day Support Waiver for individuals on the Mental Retardation Waiver waiting list was implemented on July 1, 2005, having appropriations for 300 slots. A Joint Legislative and Audit Review Commission (JLARC) study of Medicaid Waiver reimbursement rates has been completed. All of the positive steps, and many more not reflected above, are important components to enabling people with disabilities in Virginia to experience maximum independence and inclusion into all facets of community life.

Despite these encouraging developments, Virginia’s service system for persons with disabilities has significant shortcomings that must be addressed by its citizens, policymakers, advocates, and providers. The Board has attempted to identify the most significant issues affecting persons with developmental disabilities. The Board recognizes that, in all likelihood, this Assessment has not addressed all of the issues which its constituents would deem important, and that it may have raised issues with which some individuals, agencies, or organizations would not agree. The Board hopes and anticipates, however, that productive discussion of these issues and recommendations will occur and promote continued movement forward and effect positive change. A brief summary of some of the primary concerns and recommendations follows.

An ongoing theme identified by the Board throughout this assessment is that services to persons with disabilities are administered in **highly compartmentalized systems** at both the state and local levels. Critical disability services in Virginia are provided by over fifteen distinct state agencies. Collectively, these agencies are responsible for hundreds of separately administered local offices, boards, councils, commissions, programs, and other entities. In some cases, local administrators have great latitude in how they assemble funding and in what services they offer. Federal and state funding streams and regulatory processes (which sometimes flow from the state level to localities and sometimes bypass state and even local authorities) add to this complexity as does the number and diversity of individual public and private non-profit and for-profit service providers. Although the goal of those funding and regulatory processes is to provide service flexibility to best identify and meet local needs, the result is a complex, sometimes overlapping, multi-tiered system. The system has so many different sources of information and points of entry and access, that it is difficult to understand, monitor and utilize the services. This is true whether one is an administrator, regulator, individual with disabilities, or provider. Intertwined responsibilities for funding, licensure, eligibility-determination, management, and oversight results in real and perceived conflicts of interest within and between agencies at all government levels.

Much of Virginia’s fragmented service system is structured around historical definitions of disability or within very specific service “silos” based on either disability or type of service. The service system clearly lacks a person-centered focus and a lifespan design. This is most evident regarding persons with developmental disabilities who do not have a concurrent diagnosis of mental retardation. Although implementation of the DD Waiver was a critical step in the right direction, Virginia, unlike in other states which have a more inclusive system of services, does not have a state entity designated with responsibility for policy development, service planning, or service provision regarding the population of persons with developmental disabilities. Unlike individuals with a diagnosis of mental retardation, people with

developmental disabilities do not have a “home”, i.e., a **dedicated funding stream or service system** to meet their needs. The result is that the service system fails to identify, account for, or plan for the needs of numerous individuals because the nature or severity of their disability does not fall within traditional definitions and the established service system structure.

Funding for **community based vs. institutional services** for persons with developmental disabilities in Virginia has lagged behind most of the nation. The University of Colorado’s 2005 *State of the States in Developmental Disabilities* reports that Virginia is 50 out of 51 (50 states plus the District of Columbia) in this area. Other equally concerning statistics from this report are cited in the Assessment. There remain lengthy waiting lists for the Mental Retardation and Developmental Disabilities Waivers with funding lagging well behind established and projected needs. Low and inequitable rates paid by different agencies to providers of the same services are also restraining the development of community infrastructure as is the lack of a geographic rate differential for providers in high cost areas.

Adding to the complexity of restructuring the service system in Virginia, the condition of several of the Commonwealth’s state-operated institutions has deteriorated to the point where the safety and health of residents is a major concern. In December 2005, the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) completed *House Document 76, The Cost and Feasibility of Alternatives to the State’s Five Mental Retardation Training Centers*. This report to the Governor and the General Assembly proposed that substantial new resources be devoted to developing community services for persons with mental retardation and that census at the Training Centers be significantly reduced over the next 8 years. At this same time, DMHMRSAS put forth a budget proposal to rebuild two Training Centers. The proposal included a welcome infusion of funds for community based services, but at a far decreased level than the amount recommended in *House Document 76*. It is unclear how the goals of *House Document 76* can be met in light of significantly decreased funding. Further, the overall DMHMRSAS Restructuring Plan still represents a continued emphasis on long term funding of large institutions. Neither the DMHMRSAS Restructuring Plan nor *House Document 76* calls for the closure of any existing facilities. While the two rebuilt Training Centers would be smaller than those they will replace, they will still be very large institutions, one having 100 beds and the other having 300 beds.

Services for children continue to face challenges. Children with disabilities, like any other child, should be able to remain in the care of their family. The limited numbers of youth in the state Training Centers is very positive. However, the Commonwealth is experiencing the development of new nursing facility beds for children, a disturbing trend. In many instances, these children leave the nursing facility to attend school during the day, leaving a question as to whether these children need to reside in an institution and whether appropriate community supports would help them stay with their families.

In the early intervention system for infants and toddlers, documented challenges include a history of: inadequate funding; inconsistent application of requirements for eligibility, evaluation, service plan development and monitoring; a lack of qualified providers and significant variability of services across the state. For school age children, reports by the

Virginia Department of Education document significant disparities between students with and without disabilities in academic achievement and graduation rates. Barriers blocking access to the general curriculum and regular education classroom remain, particularly for students with severe disabilities. Many school divisions lack adequate numbers of qualified staff for students with “low incidence” disabilities, such as visual impairment or deafness, and many do not provide adequate planning and services to students with disabilities who are transitioning from secondary to post-secondary school or employment.

As is the case nationally, individuals with disabilities in Virginia remain significantly unemployed or underemployed. According to 2000 U.S. Census data, Virginia’s population includes approximately 1,500,000 people with disabilities. Of those, only 30 percent (457,500) are in the workforce as compared to 82 percent of people without disabilities. The Commonwealth lacks a coordinated system and infrastructure designed to integrate **employment** services for individuals with disabilities in a manner that expands service capacity and that is consumer-directed and user-friendly. The existing service system is very complicated, with various agencies maintaining employment-related service options for individuals with disabilities and different points of entry for services, thereby causing duplication and confusion to both individuals and providers. In addition, substantial public comment provided to the Virginia Board for People with Disabilities from persons with disabilities seeking employment depicted a widespread concern that the programs designed to assist them in obtaining jobs consistent with their abilities and choices often had a “one size fits all” framework that did not include adequate exploration of more creative or nontraditional options.

Transportation services for people with disabilities in Virginia are managed and administered in highly compartmentalized systems at both the state and local level. Through funding of two recent grants, the Virginia Board for People with Disabilities has been directly involved in the assessment of barriers and needs in this area. As detailed in the Transportation chapter, inadequate, unreliable, or inaccessible public transportation services significantly contribute to dependency—fiscal and personal—for individuals with disabilities. Because of unnecessary difficulties in getting to the services necessary for basic health, welfare, and safety, the likelihood of unnecessary institutionalization increases, and the likelihood of successful transition from institutional settings to community living decreases. Current planning structures are disjointed. More importantly, transportation need assessments and planning too often fail to routinely consider the interests and concerns of persons with disabilities.

Demand for affordable, accessible **housing** continues to grow while gaps between rising housing costs and limited incomes of people with disabilities continue to widen. Efforts to address these problems have been largely ineffective due to inadequate and inconsistent planning and coordination over time and in relation to transportation and other interrelated service needs. This lack of coordination further restricts options and opportunities for people with disabilities to live in communities rather than institutions. Continued stereotyping of people with significant disabilities also contribute to community resistance to and hamper development of integrated, affordable, and accessible housing. Despite numerous housing studies conducted over many years, progress and action to remedy identified problems remains elusive.

The affordability and accessibility of **health care** and the shortage of specialty providers are significant general concerns for people with disabilities. Among healthcare services, the lack of adequate, affordable dental care is most urgent. In addition to being a health concern in and of itself, poor dental care is a major contributor to poor general health.

Recommendations: The Virginia Board for People with Disabilities has made specific recommendations addressing these and many other critical issues at the conclusion of each chapter of this report. The following are some of the recommendations that reach across service areas or require additional emphasis.

The Commonwealth should eliminate the current **dual system of services**, replacing its institution (medically) based service model with a defined core set of community based services and supports that are available on an equitable basis statewide. To facilitate this, the Governor should strongly consider bringing in an outside expert from a state which has successfully made the transition from an institution to a community based system to provide technical assistance to the Governor's Office, the General Assembly, and responsible agencies in order to identify "best practices" models of service systems and to help guide necessary system changes.

In the long term, the Commonwealth may wish to consider consolidation of Medicaid **Home and Community Based (HCB) Waivers** rather than continuing to develop disability specific waivers that promote the disability "silos" discussed above. However, consolidation should only be considered if meaningful choice is provided for all services. Current HCB Waivers should be redesigned to increase flexibility and to include all supports and services that can be provided through ICF-MR funding. Mental Retardation and Developmental Disabilities Waiver slots should be funded in sufficient numbers to move people off the HCB Waiver waiting lists at a reasonable pace. HCB Waiver recipients should be provided choice of providers for all HCB Waiver and Medicaid State Plan services as provided for under state and federal regulations.

Service **provider rates** should be increased to help ensure that direct care workers receive a competitive wage and to enable providers to attract and retain trained, capable, and committed direct care workers. Virginia should follow the lead of states that have implemented initiatives to increase wages and provide benefits to direct care workers. Consumer directed support options should continue to be expanded to provide greater flexibility in recruitment and pay options. The Commonwealth should also consider incentives for new providers, including start-up funds for capital expenditures related to development of community living options such as supervised apartments, supported living, or group homes. Comparable rates for comparable services provided by different agencies should be established.

The Commonwealth's leadership should make a public commitment to move Virginia from being provider-focused to being an **individual and family directed** service system. Person centered planning principles and practices need to be universally understood and integrated into the planning processes for all individuals receiving services regardless of the environment in which services are being provided. Person centered planning is not a new or unique concept. However, the principles and practices of person centered planning are often interpreted

differently by providers of services in an institution, case managers, and community based direct support professionals. The development of a statewide planning process that demonstrates the values inherent in an approach that puts the person first should be aggressively implemented. Individuals with disabilities and their families, as appropriate, should be provided with adequate information on potential community living alternatives and have the opportunity for community experiences that will enable them to explore personal choices and support options.

Responsible agencies should work with families and community providers to address **quality of life and safety concerns**. While there will always be a critical role for oversight and monitoring, oversight by itself will not adequately address quality of life issues. Responsible agencies should work with families and community providers to explore creative options for building networks and supports around individuals. While exploring these options, the Commonwealth should ensure that Medicaid quality standards are fully implemented and develop additional mechanisms that go beyond ensuring that minimal licensure requirements are met, including assessments which monitor and promote quality of life.

Virginia needs to take immediate steps to broaden Medicaid coverage to include **dental care** for adult Medicaid recipients with disabilities. Steps also must be taken to ensure that dental service is available in all Virginia localities where it currently is not and to increase the pool of available practitioners statewide.

Virginia needs to move forward with an **integrated transportation planning** structure which will enable the State to leverage resources to better serve all of its citizens. Coordinated transportation should be utilized to the maximum extent possible. While specialized transportation services are needed in some cases, many individuals with disabilities are able to ride public transportation, utilizing either fixed routes or demand response services. There are communities that have been very well served by specialized transportation and which have developed effective partnerships with other agencies and service providers. However, these cases are not the norm; and in most instances, special transportation in which an agency operates its own fleet of vehicles and transports only its own clientele, is neither cost nor capital-efficient.

A mechanism should be developed at the Executive level for improved comprehensive and coordinated action by state agencies to reshape the structure and scope of support for **affordable and accessible housing choices** for individuals with the full range of disabilities. All available housing resources should be utilized, not just those targeted to “special needs” populations. For example, in some states housing officials have combined mainstream Low-Income Housing Tax Credit funds and Shelter Plus Care subsidies to create new supportive housing options for very low-income homeless people with disabilities. In addition, people with disabilities should be prioritized for rent assistance.

This Assessment will be updated and distributed biennially as a planning and resource document for the Governor, legislators, policymakers, individuals with disabilities, service providers, and advocates who are working together toward positive change in Virginia’s service system for people with disabilities.