

# Biennial Assessment

*of the*

Disability Services System  
*in Virginia*



**Executive  
Summary**

**Progress, Concerns,  
and  
Recommendations**

VIRGINIA BOARD  
FOR PEOPLE WITH DISABILITIES

THE COMMONWEALTH'S DEVELOPMENTAL DISABILITIES PLANNING COUNCIL

*April 2008*

This document contains excerpts from the

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

**April 2008 Edition.**

The full text of this report is available at [www.vaboard.org/biennial.htm](http://www.vaboard.org/biennial.htm)  
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This publication was funded through federal monies provided under the Developmental Disabilities and Bill of Rights Act and State General Funds.

## 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 **2008 Biennial Assessment of Virginia's Disability Services System**. The Assessment is conducted in accordance with the Board's statutory authority and responsibility under the *Code of Virginia*, § 51.5-33(2), and the federal Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402, 2000) and is consistent with the Board's mission:

To enrich the lives of Virginians with disabilities by providing a **VOICE** for their concerns.

**V**isions of communities that welcome people with disabilities  
**O**utreach to individuals, families, and advocates  
**I**nnovation through grant projects and sponsored programs  
**C**ollaboration with providers of disability services  
**E**ducation of policymakers on disability issues

As noted in the Preface, the Assessment is primarily but not solely focused on the population of individuals with developmental disabilities. The DD Act defines "developmental disability" as:

a severe, chronic disability of an individual that: (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency; and (v) reflects the individual's need for a combination and sequence of special, inter-disciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated. It includes children birth to age 9 who are likely to meet these criteria later in life.

### **Background:**

Federal and state legislation direct the Board to engage in varied activities that include but are not limited to: outreach, training, and education, coalitions building, and helping to guide public policy to effect systems change on behalf of individuals with developmental disabilities. As the Commonwealth's DD Planning Council, the Board represents an independent voice and a source of information on many issues affecting its constituents. The Board's work is enhanced by its diverse membership, which includes individuals with disabilities, family members, advocates, government officials, service providers, and various private-sector interests.

Over the past three decades, the Board has provided millions of dollars of federal funding and has leveraged significant amounts of local government and private-sector funding to promote

the demonstration, implementation, and replication of policies, programs, and practices designed to move the disability service system forward. The Board's current funding level of approximately \$1.5 million per year, however, can address only a very small proportion 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 Board's *Biennial Assessment* process provides an ongoing mechanism to report, evaluate, and make recommendations regarding the scope and effectiveness of the state-funded service delivery system in meeting the current and future needs of persons with developmental and other disabilities. As with the 2006 edition, the 2008 Assessment is designed to serve as a resource for individuals with disabilities and their families, legislators, political leaders, policy analysts, advocates, and other stakeholders. Comparative data are provided, when available, for state Fiscal Years (FY) 2005 and 2007, and for multiple fiscal years in some instances.

### **Major New Statewide Initiatives:**

Since publication of the *2006 Biennial Assessment of the Disability Services System*, many positive steps have been taken to address the needs of Virginians with disabilities. Virginia leads the nation by having a **Community Integration Advisory Commission (CIAC)** with a majority of its members having disabilities. The CIAC was established by statute in 2006 and given responsibility to monitor implementation of the Commonwealth's community integration activities and to make recommendations to the Governor. In 2007, the Governor issued **Executive Directive No. 6** reauthorizing the Community Integration Implementation team, comprised of 21 state agencies, local governments, and advocacy representatives. The directive requires collaboration "to complete and annually update a comprehensive, cross-governmental strategic plan designed to assure community integration of Virginians with disabilities." A plan was submitted in August 2007 that addresses community services and supports, self-direction, employment, housing, transportation, and workforce strategies. The plan, progress of which is monitored quarterly, is designed to both create opportunities for people to leave institutions if they wish and help people in the community avoid unwanted institutionalization.

Other reform initiatives have begun that will have a significant impact on the quality and scope of community disability services and supports statewide, reduce reliance on institutional care, and strengthen community services. The Commonwealth successfully applied for three major federally funded projects that, together, will reduce the state's reliance on institutional care and will improve community services capacity. Involvement of Virginians with disabilities is promoted for the workgroups and committees implementing these projects.

To strengthen community supports, the **Money Follows the Person (MFP) Rebalancing Demonstration Project** will facilitate transition of 1,041 seniors and individuals with disabilities to community placements of their choice over the next three fiscal years (FY 2009–2011). To accomplish this, the MFP Project will enrich services provided under several Medicaid home- and community-based waivers and address housing and transportation needs. Moreover, Virginia has chosen to make permanent all waiver and related system improvements after the project ends. The four-year MFP project, which began in FY 2008, brings \$28 million in federal funds to Virginia.

Virginia also received a **Systems Transformation Grant (STG)**, a Real Choice Systems Change Grant for Community Living, through the Centers for Medicare and Medicaid. This five-year grant provides \$2.2 million in federal funds to create a statewide “No Wrong Door” portal to be called “Easy Access” for locating services and supports; foster Person-Centered Practices in regulations, policies, and procedures across service systems; and develop a database for monitoring critical incidents and quality assurance, among others. The **State Profile Tool (SPT) Grant** provides funding for development of an outcome measurement tool that will enable progress tracking, including availability and performance, of long-term support services to seniors and persons with disabilities. Virginia will work in collaboration with eight other states in developing this tool, which will ultimately result in national outcome measures on those services. A Leadership Team, comprised of aging and disability stakeholders, has been formed to support and assist all three of these federally funded projects.

The 2006 budget actions by the Governor and General Assembly included funding to the Department of Medical Assistance Services (DMAS) for the development and implementation of a new **Alzheimer’s Assisted Living Waiver**. A reimbursement rate by 3 percent for personal care under all waivers and by 5 percent for skilled nursing services was provided through the **Technology Assisted Waiver** and the **HIV/AIDS Waiver**. Fiscal support was also provided for implementation of the **Program for All-Inclusive Care for the Elderly (PACE)**, administered by DMAS, and the **Virginia Public Guardianship Program**, administered by the Virginia Department for the Aging. Additional funding for Home and Community Based Waivers was as follow for each year of the biennium:

<b>2006 Budget Actions</b>	<b>FY 07</b>	<b>FY 08</b>
MR Waiver slots for Children younger than 6	110	0
MR Waiver slots for Children 6 and older and adults	115	0
MR Waiver facility discharge slots for persons transitioning from Training Centers to Community	80	69
DD Waiver slots	65	0

The Governor and the 2006 General Assembly charged DMAS with developing options for Medicaid reform focusing on care coordination. In response, DMAS collaborated with multiple stakeholders to develop its **Acute and Long-Term Care Integration (ALTC)** program. ALTC is designed to help Medicaid-enrolled seniors and individuals with disabilities remain independent and reside in the setting of their choice for as long as possible through a streamlined “primary, acute, and long-term care service delivery system that offers ongoing access to quality health and long-term care services, care coordination, and referrals to appropriate community resources.” ALTC enables persons who have dual eligibility in Medicaid and Medicare, as well as individuals in certain areas of the Commonwealth who use the Elderly or Disabled with Consumer Direction (EDCD) Waiver, to receive both their health care and long-term support services through a single delivery system. During the next biennium, the two initiatives under ALTC, the **PACE** program and the **Regional Model for Integrated Services**, will be expanded. Under the regional model, individuals will be enrolled in a new managed care program that will offer ongoing access to high quality health and long-term support services,

coordinated benefits between Medicare and Medicaid, care coordination, and referrals to appropriate community resources. Program implementation statewide is targeted for January 1, 2009.

Two changes to the *Code of Virginia* became effective July 1, 2007, both of which are designed to improve service planning and coordination at the state and local levels. First, the Secretary of Health and Human Resources was established as the “lead Secretary for the coordination and implementation” of long-term policy working in collaboration with the Secretaries of Transportation, Commerce and Trade, and Education, and the Commissioner of Insurance. (§ 2.2-212). Second, all local regional Planning District Commissions must now include the needs of seniors and persons with disabilities in development of their comprehensive plans. (§ 15.2-2223).

In 2007, the Governor and General Assembly took a number of actions to improve services to individuals with disabilities. The **Comprehensive Services Act (CSA) for At-Risk Children and Youth** was amended to expand eligibility for CSA-funded services to youths whose mental illness or behavioral challenges put them at risk of foster care placement. Localities have raised concerns, however, regarding the cost of serving an expanded population, and at the time of this report numerous CSA legislative and budgetary initiatives, reflecting the complexity of issues surrounding this program, were pending in the 2008 General Assembly.

Other 2007 budget actions included fiscal support for a number of disability-related initiatives, including, but not limited to: continued development and expansion of the **No Wrong Door** system of long-term care access for the elderly and persons with disabilities, funding for the **Program for All-Inclusive Care for the Elderly (PACE)**, and increased financial support to **Centers for Independent Living** and **brain injury services**. The **personal needs allowance** for nursing home residents was increased from \$30 to \$40 a month. Southside Virginia and Southeastern Virginia Training Centers were each appropriated \$200,000 for **Regional Community Support Centers** to provide outpatient services.

The 2007 General Assembly approved a 10 percent **reimbursement rate increase** to providers of congregate residential group home services for individuals using the MR Waiver and a 15 percent **rate differential** for services provided in Northern Virginia under the MR, DD, and Day Support Waivers. As a result of individuals transitioning from training centers to the community at a slower rate than anticipated, moneys for 32 of the 80 **MR Waiver facility discharge slots** approved during the 2006 session were reallocated to fund the MR Waiver for individuals residing in the community. Additional funding for new Waiver slots was also provided for the final year of the biennium as follows:

<b>2007 Budget Actions</b>	<b>FY 08</b>
<b>MR Waiver Slots</b>	330
<b>DD Waiver Slots</b>	100

Including the aforementioned reallocation of facility slots, total *actual* Waiver slot allocations for FY 2007 and 2008 were:

<b>Final Waiver Slot Allocations for 2007/2008</b>	<b>FY 07</b>	<b>FY 08</b>
<b>MR Waiver Slots for Children younger than 6</b>	110	0
<b>MR Waiver slots for Children 6 and older and adults</b>	145	399
<b>MR Waiver facility discharge slots</b>	48	69
<b>DD Waiver slots</b>	65	100

In spite of the economic downturn, the 2008 General Assembly approved additional support for disability services. An additional \$200,000 was approved for **brain injury services**; \$5,000,000 was appropriated for each year of the biennium to increase by 3.6 percent **reimbursement rates** paid to MR Waiver congregate residential group home providers. Funding for **MR and DD Waiver** slots for the FY 2009–2010 biennium was approved as follows, pending final action by the Governor (on the budget as a whole):

<b>Pending 2008 Budget Actions</b>	<b>FY 09</b>	<b>FY 2010</b>
<b>MR Waiver Slots for Money Follows the Person</b>	75	75
<b>DD Waiver slots for Money Follows the Person</b>	30	0
<b>MR Waiver slots (phase in over biennium)</b>	600	0

Despite significant growth in the DD Waiver waiting list, no additional funding was appropriated for **DD waiver slots** other than the very limited number targeted to the Money Follows the Person initiative. This again demonstrates the necessity of a state agency to address the needs (funding, policy, planning, and programmatic) of individuals with developmental disabilities as a whole, not just those with intellectual disabilities. In addition, while the addition of 600 **MR Waiver slots** appears substantial, the rate of state funding compared to the rate of waiting list growth assures that the Commonwealth will continue to lag significantly behind identified need.

Positive developments are underway. The Department of Rehabilitative Services has implemented a three-year federally funded **Partnership Implementation Grant** that focuses on strengthening the state's infrastructure for the provision of services to this often-underserved and unidentified population. The Joint Commission on Health Care (JCHC) and the legislative Disability Commission have taken a significant interest in ensuring that the needs of persons with **autism spectrum disorders** are served. A JCHC stakeholder workgroup met during 2007 to discuss creation of a state office that would serve persons with autism. The workgroup recommended that the Secretary of Health and Human Resources be asked to develop an implementation plan that would determine the agency to serve this population and whether the responsibility should be expanded to developmental disabilities rather than just autism. Budget language for the implementation of this plan was not passed by the 2008 General Assembly; however, a legislative study on best practices in autism was passed and will be conducted by the Joint Legislative and Audit Review Commission (JLARC).

Despite these encouraging developments, Virginia's service system for persons with disabilities still has significant shortcomings that must be addressed by its citizens, policymakers,

advocates, and providers. As seen at the end of each chapter, 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 that its constituents would deem important, and that it has raised issues with which some individuals, agencies, or organizations would not agree. The Board hopes, however, that productive discussion of these issues and recommendations will occur and will promote continued movement toward positive system change. The following brief summary highlights progress and improvements as well as key areas of concern reported in each chapter.

### **Progress and Concerns:**

**Early Intervention** Services addressing the needs of infants and toddlers with disabilities have expanded and improved. From FY 2003 to 2008, the General Assembly provided significant increases in financial support for Part C services, raising the annual General Fund allocation from \$125,000 to \$7,203,676. Between FY 2002 and 2006, the number of infants and toddlers served under Part C increased by 12 percent; however, these increases have not been proportionate with the level of increased funding. The Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS), responsible for Part C administration, is engaged in strengthening oversight and improving both fiscal and program data collection. Solutions Consult Group, Inc., under contract to DMHMRSAS, has conducted comprehensive study of the Part C system and has made numerous recommendations for programmatic and fiscal improvements. DMHMRSAS has provided training and technical assistance throughout the Commonwealth, and compliance on several key indicators of services to children has improved. That the number of infants and toddlers served in their natural environment now stands at 99 percent is one such notable improvement. Despite these efforts, however, Virginia still lags behind other states in the percentage of eligible children served, particularly those served between birth and age one. Service variability among localities remains a challenge as does provider shortages.

**Education:** Between FY 2006 and 2007, funding for special education services for students with disabilities increased by 15 percent. The *State School Report Card* for 2006–2007 indicates that only 3 percent of core academic classes were taught by teachers not meeting the federal definition of “highly qualified,” although the percentage was higher (5 percent) in high poverty areas. A positive development was the revision by the State Board of Education of *Virginia’s Licensure Regulations for School Personnel* (8 VAC 20-22-10 et. seq.). As a result of this change, described in more detail in the Education chapter, a broader pool of educators will be available to work with students who have diverse abilities and needs. VDOE has also continued a focus on better measurement of educational outcomes of students with significant disabilities and on improving services to students with autism. Among the many continuing challenges affecting families and students with disabilities are access to the general curriculum by students with severe disabilities, appropriate inclusion of these students in the state’s accountability system, receipt of services in the least restrictive environment, low graduation rates, disparity in achievement as compared to students without disabilities, and access to assistive technology.

To address 2006 changes in federal regulations, the VDOE has obtained, and continues to seek, public comment on its draft revision of *Regulations Governing Special Education Services for Children with Disabilities*. The current draft includes some positive provisions such as maintaining age 14 as the point at which transition services must be provided. The proposed regulations, however, also have provisions of concern to the Board and families including, but not limited to, those that permit school staff members to be voting members of Local Advisory Committees and that eliminate the requirement for parental consent for partial or full termination of special education and related services.

**Community Living Supports:** Since fiscal year 2005, increasing numbers of Virginians with disabilities have been able to gain access to services in the community rather than in institutional settings. As noted earlier, 2006 budget actions significantly increased funding enabling Virginians with disabilities to maintain natural supports in their communities. Most important, the number of individuals with disabilities served under various Medicaid Waivers increased as a result of new allocations. New Medicaid services targeting the elderly have been implemented. The Virginia Assistive Technology System (VATS) expanded its AT recycling network to provide AT equipment to those who otherwise cannot afford it. From FY 2005 to 2007, the number of persons with intellectual disabilities who received services through Community Services Boards increased by 6.8 percent. During that same period, the number of people served under the Public Guardianship and Conservatorship Program more than doubled, the number of youth served under the Comprehensive Services Act (CSA) increased by 13.6 percent, and the number served under the Department of Rehabilitation Services' (DRS) Community Rehabilitation Case Management program increased by 10.5 percent.

Despite more people being served, the disability service delivery system remains underfunded to meet current needs, and progress is threatened by the 2008 economic downturn. A major challenge is the growing waiting lists for the MR and the DD Medicaid Waivers. From 2005 to 2007, the number of persons on the DD Waiting List more than doubled, increasing from 284 to 591 individuals, and those on the MR Waiting List increased by 7.2 percent. Moreover, according to DMHMRSAS data, since July 2004, the number of persons on the MR "Urgent" Waiting List has grown by more than one person per day. For persons with brain injury, from FY 2005 to 2007 the waiting list for the DRS Personal Assistance Services grew from 7 to 54 individuals. Funding for state agency staff members to provide licensure and quality assurance oversight, essential to ensuring citizen safety and service effectiveness, has not kept pace with increases in the level of community services. Both workforce development and expansion of service capacity will continue to be critical areas for funding. System fragmentation, low provider rates, inadequate person-centered practices, and the lack of a designated agency for developmental disabilities remain significant obstacles to effective planning, coordination, delivery, and oversight of state-funded services.

**Institutional Supports:** Trends in this area have been mixed. Between FY 2004 and 2007, the number of youths younger than age 21 served in nursing homes/facilities declined significantly, but the number of residents increased by 4 percent overall, primarily among adults ages 21–64 years. According to the DMHMRSAS *Comprehensive Plan for 2008–14*, efforts are underway to effect "a cultural transition" at state-operated Training Centers toward providing

time-limited care of less than one year to individuals with intellectual disability and co-occurring mental illness or behavioral challenges. At state Training Centers between FY 2005 and 2007, the average daily census decreased by 7 percent, and the number of operational beds, by 4.8 percent, with almost all of the decline limited to Central Virginia and Southside Virginia Training Centers, the two largest and oldest facilities. Annual per capita costs for state Training Centers rose significantly (15 percent) during that time period. A lack of ongoing discharge planning and the restrictive “ready for discharge criteria” that apply to persons residing in Training Centers are obstacles to transitioning facility residents into the community.

By comparison, between FY 2005 and 2007 the number of non-state-operated ICFs-MR statewide increased from 25 to 31 (24 percent), while annual per capita costs rose by 30.9 percent. Inadequate and sometimes inaccurate information is provided to families and guardians regarding community options, and there continues to be a widespread misperception that persons with significant disabilities, particularly those with complex medical needs, cannot be served in other than an institutional setting.

**Health Supports:** During the past two years, health care has received considerable attention. Challenges in health care include a shortage of medical and dental providers willing and able to work with individuals with disabilities, as well as attitudinal and cultural barriers. Coordination and continuity of care is problematic, particularly for persons with developmental disabilities who have co-occurring medical or mental health conditions, and user-friendly information related to health care and disease prevention is not readily available to persons with disabilities and their families. In 2006, through a federal grant and seed money from DMHMRSAS, Medical Home Plus was created in Central Virginia to improve care coordination for children with disabilities and special health needs. Medical Home Plus has continued its efforts on behalf of families and children through a coalition involving pediatric practices, Care Connection for Children, Family Voices, Parent to Parent, the Department of Health, and the Virginia Chapter of the American Academy of Pediatrics. In 2007, a dental summit and two major conferences were held, both of which addressed improving medical care to individuals with disabilities. The Governor’s Commission on Health Reform conducted a comprehensive study during 2006–2007 and, after receiving considerable public comment, published its report in the fall of 2007. This report identified major trends and issues in areas that included, but were not limited to, workforce development, prevention, long-term care, and transparency, and made numerous specific recommendations on how to improve service delivery in the coming decade.

**Community Housing:** A number of agencies are collaborating to improve the availability and accessibility of housing for individuals with disabilities in Virginia. Work is being done under the auspices of the Office of Community Integration, the Money Follows the Person Demonstration Initiative, and the Statewide Council on Independent Living. Projects supported by the Virginia Board for People with Disabilities include the Housing and Transportation Alliance and the EasyLiving Home voluntary certification program, described in the Housing chapter. These efforts have all generated important public-private partnerships throughout Virginia. Another positive development was action by the 2007 General Assembly to expand and rename an existing “visitability” home modification tax credit to include new home construction that meets specific universal design requirements.

Despite these positive initiatives, waiting lists for Housing Choice Vouchers remain large, 6,633 as of November 2007, and the majority of local public housing authorities (PHAs) have stopped taking applications for this program. Based on DMHMRSAS data, the Static Capacity for Community Services Boards' intellectual disability residential services increased only 2 percent between FY 2005 and 2008, and the length of wait time ranged from nearly a year (49.5 weeks) for Supported Residential Services to a little more than two years (106.4 weeks) for Intensive Residential Services. Overall, affordable housing options are extremely limited, particularly for accessible housing. Housing continues to be frequently linked to receipt of services, limiting choice and fostering a medical model for service delivery. Some communities remain resistant to the development of housing for people with disabilities (e.g., group homes), and fair housing complaints based on landlord bias show that disability discrimination is now the cause of most claims.

**Transportation Services:** Reliable, accessible transportation is essential to Virginians with disabilities not only to obtain and keep basic services but also to participate fully in community life. Lack of reliable transportation is also a key barrier in the ability of individuals with disabilities to obtain or maintain employment. Statewide, public and paratransit transportation services are often inadequate, especially in rural areas. Quality assurance problems remain for transportation provided under the Medicaid brokerage system. Coordination between housing and transportation planning and overall service capacity are inadequate and the lack of uniform, consistent data collection regarding existing transportation resources and both capital and operational costs is a key system challenge. Establishment of a Memorandum of Understanding (MOU) related to Coordinated Human Service Transportation in Public and Nonpublic Transit Systems in 2007 was a notable step forward. Signed by both the Secretary of Transportation and the Secretary for Health and Human Resources, this MOU requires all state agencies funding transportation for persons who are elderly, have low income, or have disabilities to participate in an Interagency Coordinating Council tasked with improving transportation coordination and services as well as reducing duplication. It also requires development, implementation, and monitoring of work plans designed to meet those goals.

**Employment Services:** Coordination among the many agencies responsible for employment or employment training activities remains a challenge. Employment statewide remains low with approximately two-thirds of adults ages 18–64 with disabilities not employed. Vocational services provided by the Department of Rehabilitation Services (DRS) have been under an Order of Selection since 2004, and during FY 2007 and 2008 service eligibility was limited to those individuals with significant disabilities. Virginia lags behind other states in its support of customized and supported employment opportunities, maintaining numerous facility-based, “sheltered” programs. Financial disincentives for employment remain, and fewer than anticipated have enrolled in Medicaid Works, the Buy-In program designed to enable individuals with disabilities to be employed and maintain their Medicaid benefits. Physical and program accessibility at many of the Workforce Board One-Stop centers remains inadequate. Since 2006, however, the federally funded Disability Program Navigator (DPN) initiative has successfully assisted some One-Stop Centers in becoming fully accessible and has enhanced employment services and outreach to individuals with disabilities. DPN funding ends in FY 2008.

In other positive developments, the Governor issued Executive Directive No. 8 in the fall of 2007, requiring all executive branch agencies, including institutions of higher education, boards, and commissions, to review relevant hiring practices and “to expand existing efforts for recruiting, accommodating, retaining and advancing people with disabilities for positions available in state government.” Executive branch agencies must annually report on efforts to hire persons with disabilities and to appoint them, as appropriate, to boards and commissions. An important step was taken by the 2008 General Assembly to eliminate the significant disparity between the supported employment rates paid under Medicaid home- and community-based waivers versus the much higher rates paid by the vocational rehabilitation system. Passage of budget language requires that the Department of Medical Assistance Services (DMAS) “realign the rates paid for individual supported employment provided under Medicaid home- and community-based waivers to the same level paid by DRS to employment services organizations.” This change, effective July 1, 2008, also requires that DMAS change its rates whenever DRS does so.

**Advocacy and Information Resources:** To ensure accessibility, availability, and affordability of needed disability services, effective advocacy services across the individuals’ life span are essential. Many organizations work effectively to provide information and technical assistance and to help individuals with disabilities and their families participate in community life and maintain natural supports. Individual advocacy resources remain limited, however, because of both fiscal and program eligibility constraints. Noteworthy progress has been made to involve individuals with disabilities and advocacy groups in planning and developing services, as exemplified by the system transformation efforts led by the Office of Community Integration, the Department of Medical Assistance Services, and the Department of Mental Health, Mental Retardation and Substance Abuse Services. Adoption of “person first” language more respectful of people with disabilities in state laws and regulations is being pursued. As a result of excellent work by self-advocates, the 2008 General Assembly passed a bill that would change references in the *Code of Virginia* from mental retardation to intellectual disability. The change, however, is contingent on the bill’s being passed again by the 2009 General Assembly.

Public comments received by the Board indicate that with respect to information resources, state agency Web sites offer challenges. They were found by persons with disabilities and family members to be complex, use bureaucratic jargon, or have outdated information. Since laws, regulations, policies, and practices change over time, state agencies and organizations must consistently provide accurate, reliable information to individuals and their families about their rights and about available resources, best practices, and community opportunities.

**Emergency Preparedness:** In light of growing state and national efforts to address response to natural and other disasters, this edition features this new chapter. During FY 2006–2007, progress occurred at many levels to improve inclusion of persons with disabilities in developing emergency plans and in sheltering-in-place. In 2006, considerable efforts were made to include individuals with disabilities in statewide Community-Based Emergency Response Seminars held by the interagency delegation to the Working Conference on Emergency Management and Individuals with Disabilities and the Elderly. The Virginia Department of

Emergency Management (VDEM) continues to promote participation by people with disabilities in the creation of policies and procedures that will affect them. VDEM also created a Vulnerable Populations Committee, chaired by Disability Services Agency staff members. The Office of Commonwealth Preparedness has assembled regional teams that include individuals with disabilities to develop preparedness and shelter plans.

Emergency preparedness activities are evolving, but improvements are still needed. Individuals with disabilities and advocacy organizations still are not systematically engaged in discussing the contributions that they can make in emergency planning and, typically, have not been invited to participate actively in planning and conducting disaster response training exercises at the local, regional, or state levels. More opportunities are needed to bring together individuals with disabilities and emergency response and public safety personnel with direct evacuation and sheltering experience so that they can share knowledge and “lessons learned.” The availability and mapping of shelters meeting uniform standards remains an issue, and much work must still be done to plan shelters for individuals with specialized medical needs. Lack of adequate transportation options for individuals with disabilities living in the community and residing in congregate settings remains a continuing gap and a critical need. Additional public education on personal emergency plans and available resources is needed for all citizens.

### **Recommendations:**

In this Assessment, the Board states concerns and makes recommendations addressing them not simply to improve the quality and scope of services for Virginians with disabilities, but also to promote sustained movement toward a comprehensive continuum of community care. It is unnecessary and would be redundant for this Executive Summary to review and describe all of the many recommendations contained in this report; however, the list below provides a summary, by service topic, of the areas in which the Board would like to see action and change. A full description and rationale for each recommendation may be found at the end of the appropriate chapter.

A core value underlies all of the Board’s recommendations. State-funded services should, to the maximum extent possible, promote options, including residential choice that foster self-determination, independence, choice, and interaction with fellow citizens who do not have disabilities. This closing quotation from disability advocate John O’Brien provides a context for the Board’s recommendations:

Many people with developmental disabilities continue to lack connections beyond their relationships with their families and other people in the human service settings they attend. This reflects a history of discrimination against people with developmental disabilities which is expressed in multiple barriers to social integration. Though good services can help people to overcome these barriers, it usually takes conscious, sustained work....

Most “integrated” services for people with developmental disabilities and their intended outcome, “enabl[ing] individuals with disabilities to interact with non-disabled persons to the fullest extent possible,” are best understood as means to

personally and socially worthwhile ends.... Participation, membership, and friendship are the ends to keep in view when working to assist people with developmental disabilities to live a satisfying life in their community. ... The best predictor of personal safety and freedom from abuse and neglect is having intimate relationships and having friends.

**References:**

O'Brien, John. (2006). *Perspectives on "Most Integrated" Services for People with Developmental Disabilities*. Lithonia, Georgia: Responsive Systems Associates. Retrieved from: [http://thechp.syr.edu/most\\_integrated.pdf](http://thechp.syr.edu/most_integrated.pdf).

## II. Early Intervention

### Areas of Concern for Early Intervention Services

The chapter detail provides information on the breadth and depth of services available through the Part C system. Cited throughout the chapter are important statistical data regarding program activities and performance indicators. The chapter detail also provides information on areas in which the system and services have improved and describes improvement activities and outcomes. Section G focuses on the specific areas in which further improvements may be needed to move the system forward and ensure that the needs of eligible infants and toddlers with disabilities throughout the Commonwealth are met. The Virginia Board for People with Disabilities (VBPD) identified the issues and concerns below through a variety of mechanisms, including: (1) review and analysis of the numerous source documents referenced within and listed at the end of this chapter, (2) public comment received via VBPD's six public forums held throughout the state in the spring of 2007, and (3) written comment and information provided and verified by state agencies in their reviews. The issues below are not all-inclusive, but represent those that VBPD has identified as important to systems improvement.

- 1. Impact of Increased Prevalence of Autism Diagnoses:** The increasing numbers of infants and toddlers being diagnosed as having autism spectrum disorder is creating pressure on Early Intervention and public school systems nationwide and worldwide. The increase in autism diagnoses is of such concern that in 2007 the American Academy of Pediatrics put forth a recommendation that the children be tested twice for signs of autism before their second birthday. Diagnoses are beginning to be made at an earlier age and the Part C system has long served infants and toddlers with autism or pervasive developmental delay, a diagnosis that sometimes predates a formal autism diagnosis. The rising incidence of autism has also brought forth challenges with respect to providing appropriate evidence-based interventions to infants and toddlers. There are numerous interventions available, many of which may have anecdotal evidence of efficacy but no scientific research establishing them as effective interventions. Many parents of infants and toddlers with autism are seeking highly intensive treatment programs such as Applied Behavioral Analysis (ABA). Research has shown that more-intense early intervention leads to significantly improved outcomes for children with autism spectrum disorders. These interventions, however, are not universally available and they are extremely expensive. Finally, there are not sufficient numbers of qualified providers statewide trained to work with infants and toddlers with autism spectrum disorders.
- 2. Service Variability among Localities:** This issue, addressed in the 2006 *Biennial Assessment* remains unresolved. Solutions Consulting Group in its 2007 *System of Payments Summary Report* cited a lack of consistency and uniformity in provision of services as among the challenges facing the Part C system. The consultants specifically note that a variety of contractual approaches within the localities do not support the requirement to ensure consistency and uniformity in compliance with Part C requirements. This finding on local variability in the availability and quality of Part C services echoes the conclusions of the 2004 Final Report of the Department of Mental Health, Mental Retardation and Substance

Abuse Services (DMHMRSAS) Part C Infrastructure Task Force, which identified inconsistencies in the determination of Part C eligibility, evaluation of service needs, development and monitoring of required Individualized Family Service Plans, and delivery of services. These report findings, also supported by public comment in 2005 and 2007, indicate that training, skill levels, and caseloads continue to vary greatly across the state; and there is no consistent monitoring of Individual and Family Service Plan (IFSP) implementation or effectiveness resulting in wide variability of service availability, intensity, and quality. In addition, families continue to report that they often do not receive the information or supports they need at the time that it is needed, resulting in a delay in gaining access to services that could benefit the infant or toddler. Obtaining Part C (or any) services needed by one's infant or toddler should not depend on the locality in which the parents live and work.

- 3. Service Payment and Rate:** In June 2007 the *System of Payments Summary Report*, prepared for the Part C program by Solutions Consulting Group, found that although more state general funds were infused into the Part C system, the program faces continued financial challenges, described earlier in the chapter. In addition to concerns that the number of children being served has not increased proportionately with the amount of funds infused in the system, additional issues include: (1) the lack of consistent, statewide data on the functioning of the Ability to Pay system and the overall cost of Part C services; (2) the wide variability of local contributions to the system, resulting in an uneven system of services depending on where the infant or toddler resides; and (3) provider reimbursement issues, including rates, processing delays, and variability of billing "units."

Specific provider rate issues affecting the Part C system are described by Solutions Consulting Group in the *System of Payments Summary Report* as follows, (excerpted): "Contractual arrangements between providers and local lead agencies are constructed locally. Rates for services are sometimes bundled and cover a whole month. Other times a unit rate reimbursement is used. Methodology for arriving at the rate varies considerably by locality resulting in reimbursement varying from \$50–\$150/visit without any criteria to warrant differences. The same holds true for reimbursement of evaluation/assessment services. Cumbersome third party billing procedures result in significant delays in reimbursement." The report also notes that few local lead agencies "reimburse for time spent in team meetings and consultations as are required by federal regulations."

- 4. Inadequate Use of EPSDT as Funding Source:** Directly related to the payment issues discussed above is the underuse of a primary payment mechanism. As noted in the chapter detail, there are numerous funding sources available for Early Intervention services. Early Periodic Screening Diagnosis and Treatment (EPSDT) through the state's Medicaid Program provides coverage for comprehensive medical and therapeutic intervention for children up to age 21 who are eligible for Medicaid. Many families do not explore the use of EPSDT because they are not aware of these benefits. Consistent reports from the Medicaid Waiver Technical Assistance Center show that many families are unaware that if their child receives services through Medicaid Waivers, they should have access to EPSDT because their child, once declared waiver-eligible, is also eligible for state plan Medicaid. Some children who

are on a waiting list for the MR or DD Waivers may be eligible for the EDCD Waiver and if found eligible and funded would have access to EPSDT. Although the Department of Medical Assistance Services conducted an EPSDT outreach program, the program appears to remain underutilized and misunderstood.

5. **Lack of Qualified Providers:** Past funding limitations over the years have contributed to a dearth of qualified personnel, inadequate training, high turnover of Early Intervention providers, and competition for providers with local school divisions and other agencies that are able to pay more for services and staff. While funding for the system has increased significantly, capacity has not expanded to meet the need. Solutions Consulting Group in its 2007 *System of Payments Summary Report* noted a number of barriers to attracting and maintaining providers including, but not limited to, reimbursement issues, paperwork, and other requirements are seen as cumbersome by providers. Public comment received in the spring of 2007 indicated a limited choice of services and diminishing options, particularly in rural areas with limited resources. As noted above, the challenges of the increasing number of infants and toddlers diagnosed with autism spectrum disorders and requiring intensive levels of intervention have further strained the provider pool as have low provider rates.
6. **Organizational Conflict of Interest:** The Part C local lead agencies are responsible for ensuring that the local system of Early Intervention services is in place; and that the system meets all federal Part C regulations, state policies and procedures, and all fiscal and program assurances. In addition, the local lead agency, after receiving Part C funds from the state agencies, contracts or otherwise arranges with private entities for services, and can also be a provider in the local system. This results in an inherent conflict of interest, especially in those localities where the local lead agency is the **sole** provider of Early Intervention services.
7. **Gaps in Early Identification/Medical Practitioner Awareness:** Solutions Consulting Group in its 2007 *System of Payments Summary Report* noted the importance of early identification and Virginia's gaps in that area. An important aspect of early identification is continued physician awareness. Public comment continues to indicate that many pediatricians are reluctant to diagnose disability in young children, particularly for those who may be on the autism spectrum. Training and residency experience on disability identification in infancy and early childhood is a gap in most medical school curricula. Likewise, where probable disability is known, such as infants who are in the Neonatal Intensive Care Unit (NICU) unit for a significant time after birth, inadequate attention is given to addressing issues of potential long-term disability and to providing or arranging immediate Early Intervention services for babies exiting the hospital system.
8. **Challenges with Accountability and Correction of Noncompliance:** As reported in the chapter detail, Virginia's Part C system continues to have challenges with respect to compliance with federal requirements, and the Commonwealth is one of 17 states determined to be in the category of "needs assistance" in meeting the federal requirements of Part C. In reviewing areas of noncompliance and other challenges revealed by evaluators of the system, of most concern to the Virginia Board for People with Disabilities (VBPD) would be a need

for improved accountability and oversight of local systems and accounting of the use of state general fund dollars.

9. **Inadequate Parent Education and Marketing of Part C:** As with other components of the disability service system, families cite inadequate access to information or a lack of information as barriers within the Part C system. In the 1990s there was an extensive effort to market the Part C system to families and providers. The tagline “Babies Can’t Wait” became synonymous with the Early Intervention system. Posters, public service announcements, and literature were widely available. With the need to ensure that sufficient funding was available for direct service provision, marketing understandably became a lower priority. The lack of focus on providing adequate information on the Part C system, however, resulted in Child Find compliance issues (lower numbers of infants and toddlers served than appropriate or not served in a timely manner). In addition, the lack of a sustained public awareness effort has meant that that parents and professionals have less information available to them, and most seriously, infants and toddlers are referred to needed services at a later age than appropriate or not at all.

## **Board Recommendations for Early Intervention Services**

Part C Early Intervention services are an important component of the disability service system, addressing critical needs at the earliest age possible. The Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMSRAS) has engaged in a number of efforts designed to improve the Part C system, involving stakeholders at all levels. The Virginia Board for People with Disabilities (VBPD) Board supports these ongoing efforts. Many of the recommendations below represent areas that are already being reviewed by the Part C system. VBPD focuses below on those areas that it sees as most critical to improving the quality, quantity, and scope of services to infants and toddlers with disabilities.

1. **Increase Accountability and Fiscal Oversight of the Part C Early Intervention**

**Program:** As note in the chapter detail, the Commonwealth has infused significantly new funds into the system. This very positive step is commended. It is important, however, to determine why significantly more children are not being served despite increased funding. The Virginia Board for People with Disabilities (VBPD) recognizes that there may be a number of factors contributing to this including: (1) potentially increased costs of serving children in natural environments, including transportation costs; (2) potentially increased costs of serving children with more significant disabilities who may require intensive services, such as children with autism; and (3) possible reduced contributions from some localities as a result of increased state funding and the lack of any local funding requirement. These fiscal challenges need to be thoroughly examined and the use of Part C funds, federal, state, and where appropriate local, should be accounted for in a detailed, thorough, and transparent manner.

Rate issues are also a continuing challenge with respect to statewide service provision. VBPD recommends that provider rates be increased and that the rate structure fairly reimburse providers for their time. For example, transportation to and from the child’s

residence should be reimbursable as an allowable expense so that a provider who spends an hour or more commuting is not penalized.

VBPD supports the comprehensive recommendations of Solutions Consulting Group with respect to family cost participation, funding allocations, and rate structures, and recognizes that these recommendations must be thoroughly reviewed and their impact on the system assessed prior to implementation. Their comprehensive report provides important guidelines for moving forward. VBPD particularly supports the recommendation that a Medicaid State Plan Amendment for Early Intervention Services through Home and Community Based Services under Early Periodic Screening Diagnosis and Treatment (EPSDT) be developed and that the expansion of financial eligibility for this home- and community-based service be increased to 300 percent of the federal poverty level. If implemented this would free up funds for services to infants and toddlers who are not Medicaid eligible.

**2. Enhance Quality Assurance Efforts to Improve Quality and Consistency of Services:**

The Virginia Board for People with Disabilities (VBPD) commends the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) for its work on a Quality Assurance System that began following the 2003 Infrastructure Task Force established by that agency. Much work remains to be accomplished, however. As noted in the *2006 Biennial Assessment*, a quality assurance system needs to address the training and caseload size of local service providers; identify where specific improvements are required in local planning, coordination, and service delivery by public and private providers; and promote existing best practices to eliminate service gaps and inconsistencies. All of these challenges remain at present. VBPD recommends that the following issues should specifically be addressed through quality assurance efforts: (1) Why are so many children being referred to the system who do not end up receiving Part C services? (2) Why are families refusing Part C services? (3) Are all children being accounted for via an accurate child count and if not, why not? (4) What specific services are children receiving and in what amount? (5) Is the new data system adequate for addressing these issues? (6) Is the state's monitoring and quality assurance system adequate to address the issues that have established Virginia as "needing assistance"?

**3. Eliminate Organizational Conflict of Interest:** VBPD recommends that the oversight and provider roles of the local lead agency be separated to eliminate conflict of interest.

Incentives should be expanded to encourage the expansion of the Part C provider pool, particularly in areas with limited resources to help ensure an adequate choice of providers. Within the current system, VBPD recommends that DMHMRSAS closely examine whether adequate "firewalls" have been established to maximize partnerships and mitigate conflict of interest issues that can negatively affect families.

**4. Improve Family Education Efforts:** VBPD recommends a significantly increased focus on outreach to families and on family education. This is needed to ensure parents are aware of the services available under Part C and of issues relating to the transition from Part C to school age (Part B) services. VBPD recommends development of a user-friendly *Guide to*

*Part C Early Intervention Services*, similar in nature to the Guide developed by the Endependence Center under a grant from VBPD on Medicaid Home and Community Based Waivers. The Medicaid Waiver Guide is still being used by families and providers years after its first publication (having undergone necessary revisions) and is a consumer-friendly and accurate source of information in a changing environment.

- 5. Improve Medical Practitioner and Provider Education Efforts:** In addition to improving educational opportunities for families, significant effort should be devoted to educating providers. Families report that physicians, case managers, and social workers are often uninformed about the Early Intervention system and that referral to that system is delayed. VBPD recommends mandatory training of support coordinators and case managers so that they are able to give appropriate direction to families for needed services. Service providers should receive ongoing education that will enable them to implement best practices and become knowledgeable about disability-specific needs, such as working with infants and toddlers who have Autism.

Better education of medical practitioners, including physicians and nurses, who typically are the first individuals to interact with families needing services, supports, and referrals, is critical. The Part C system also needs to improve significantly the training and education of these practitioners regarding the services available through Part C and the importance of early identification. Physicians working with families whose children are in Neonatal Intensive Care Units (NICU) who are at risk of any developmental delay should be provided with information about early intervention. Although families may not “be ready” to receive this information and their child may ultimately not require services, the importance of early identification cannot be overstated. The Virginia Board for People with Disabilities (VBPD) recommends that the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) develops informational materials that are brief and concise in nature and that could be easily and inexpensively provided to all parents of infants who are in the NICU after birth. Finally, pediatricians and family practice physicians need additional education and training and readily available information regarding the Part C system. These practitioners are most likely to see infants and toddlers on a regular basis (both in private practice and public health clinics) and can be the key to identifying children in need of services at the earliest age possible.

- 6. Identify and Implement Best Practices in Autism:** VBPD recommends that as therapies and interventions are developed, the Commonwealth identify and support evidence-based practices, so that it can most prudently apply public dollars for interventions having the best outcomes and thereby save taxpayer money as well as provide the most meaningful support to families and children. VBPD supports the proposed study on Autism best practices currently pending in the 2008 General Assembly.
- 7. Implement Workforce Improvements:** VBPD recommends that a study of workforce needs in Early Intervention be conducted in light of provider shortages. Incentives should be developed to address the limited number of providers who are willing and able to provide services to infants and toddlers in their natural environment as required by federal law. The

Governor's Health Reform Task Force did an excellent job of identifying overall workforce issues in the health arena; this type of study, albeit more limited, would be useful in ensuring access to quality Early Intervention services and transparency of such services. VBPD also recommends that data collected through the quality assurance system referenced above be used to determine situations in which workforce scarcity is caused by the inability of the local early intervention system to compete with the education system for qualified personnel and to recommend corrective actions and/or incentives for providers.

### III. Education

#### Areas of Concern for Educational Services

The chapter detail provides information on the breadth and depth of services available to students with disabilities who require special education and related services. Cited throughout the chapter are important statistical data regarding program activities and performance indicators. The chapter detail also provides information on areas in which the system and services have improved and describes improvement activities and outcomes. Section G focuses on the specific areas in which further improvements may be needed to move the system forward and ensure that the needs of students with disabilities throughout the Commonwealth are met. The Virginia Board for People with Disabilities (VBPD) identified the issues and concerns below through a variety of mechanisms, including: (1) review and analysis of the numerous source documents referenced within and listed at the end of this chapter, (2) public comment received via VBPD's Board's six public forums held throughout the state in the spring of 2007, and (3) written comment and information provided and verified by state agencies in their reviews. The issues below are not all-inclusive, but represent those that the Board has identified as important to systems improvement.

1. **Obtaining an Education in the Least Restrictive Environment (LRE):** Students with disabilities are entitled to receive services in the least-restrictive environment (LRE) (i.e., be educated alongside their peers without disabilities unless their Individualized Education Program (IEP) requires otherwise. Despite this legal precept, LRE continues to be an issue raised in requests for due process and mediation and in complaints. The State Special Education Advisory Committee (SSEAC) has also continued to bring forth LRE issues as a concern. The SSEAC reports receiving ongoing public comment regarding the lack of access by students with disabilities to the general education classroom and the failure of some local education agencies (LEAs) to provide appropriate supports in the general education classroom for students with disabilities. Comments received during the 2007 Virginia Board for People with Disabilities (VBPD) public forums also reflected concerns regarding increasing use of segregated services, a perceived "mindset" of low expectations and of limitations rather than capabilities of students with disabilities, the adversarial nature of some school divisions and of the Individualized Education Program (IEP) process in general and a lack of knowledge among school staff members regarding available supports for classroom and extracurricular activities. In addition, comments were made on the lack of access to inclusive transportation. Parents expressed frustration that attitudes of local school personnel and the lack of person-centered practices presented a major barrier to inclusion. They described school staff members as viewing their children in terms of deficits and limitations rather than as possibilities. In the words of one parent, "they just don't see my son as capable." The Virginia Department of Education (VDOE) has set a number of goals designed to increase the number of students receiving instruction in the regular classroom to 68 percent by 2010.
2. **Inadequate Access to the General Curriculum:** Despite initiatives at the statewide level, meaningful access to the general curriculum by students with disabilities, especially severe

disabilities, remains an ongoing, unresolved issue. A frequent perception by parents as expressed through public comment to the Board at its 2005 and 2007 public forums is that some school administrators are focused on cost containment for students with disabilities rather than on promoting academic achievement; and that pressures related to the federal No Child Left Behind testing has contributed to attempts to dissuade parents from including their children in Virginia's Standards of Learning (SOL) curriculum. Public comment provided to the SSEAC either at meetings or through constituency reports in 2006 noted the need for (1) increased access to the general curriculum, (2) improved achievement, (3) support for effective inclusion; and (4) VDOE leadership to address these issues. Issues cited included student access to Standards of Learning (SOL) and to coursework needed to pursue an Advanced Studies or Standard rather than a Modified or Special diploma. Public comment provided to VBPD and to the SSEAC noted significant challenges for students with disabilities and their families in receiving adequate information on diploma options and course/verified credits needed to pursue various options. There is significant concern among families that they do not receive information early enough to make informed decisions on diploma options and coursework that can affect their child's future.

3. **Proposed Revocation of Student and Family Protections in State Regulations Governing Special Education:** Virginia's *Regulations Governing Special Education for Students with Disabilities* (8 VAC 20-81 et. seq.) are being revised in response to the release of new federal regulations for implementation of the Individuals with Disabilities Education Act (IDEA) 2004. Virginia's current special education regulations contain important protections for students with disabilities and their families that go beyond federal regulations in several areas, resulting in practices beneficial to these students and families. Students with disabilities, parents, and advocates have strongly advocated for the Commonwealth to maintain these critical protections. Draft regulations released in September 2007, however, eliminated some longstanding parental/student protections. These included eliminating parental consent for partial or complete termination of services, changing the use of the developmental delay label from usage up through age 8 to usage through age 5, allowing a functional behavioral assessment to be based on existing data, and removing the requirement for short-term objectives for students participating in the SOL curriculum. The Board has joined with the Virginia Coalition for Students with Disabilities to express its disappointment with respect to the unanticipated revocations of family involvement rights and student protections.
4. **Challenges in Meeting the Needs of Students with Autism:** As referenced in the Early Intervention Areas of Concern, the increasing numbers of children diagnosed as having Autism Spectrum Disorder (ASD) is also straining school systems around the nation. Data provided by VDOE and cited earlier in this chapter verify this significant growth in the school age population with ASD. Many school divisions are unprepared to give adequate service to increasing numbers of students who have autism and particularly those with behavioral challenges. In its 2006 *Annual Report*, the State Special Education Advisory Committee (SSEAC) reported receiving public comment regarding inadequate delivery of services to this growing population.

While the requirement is for each student's supports to be individualized, this may not occur. For example, parents report that if a school division has an "autism program," it is more likely that placement in it will occur making it more difficult to obtain placement in regular education with supports. Similarly, parents who would like a specialized program for their child with autism may find that such programs are not available because of a lack of school division expertise and/or the reported expense of such programs.

5. **Gaps in Secondary Transition Services:** It is very positive that under the draft *Regulations Governing Special Education Services*, the Board of Education has proposed maintaining the age for transition planning at 14, rather than 16 as stipulated under federal IDEA. Transition services, however, continue to be a significant concern—this despite concerted and ongoing efforts and resources being put into this arena by the Virginia Department of Education (VDOE) and through various grants and systems change initiatives. In 2006, the State Special Education Advisory Committee (SSEAC) noted receiving public comment on the need for better transition services and the lack of transition skills among students with disabilities exiting secondary school. Concerns were raised regarding placement of students with disabilities into non-Standard diploma options; low expectations, and students being geared toward low-level traditional jobs or sheltered workshops. Parents and advocates feel that school staff members often have low expectations regarding their children. Parents report high staff turnover in high school vocational programs and a lack of information about transition services and supports. VDOE is now collecting postsecondary outcome data on youths who had IEPs and are no longer in secondary school. Baseline data were gathered for 2006–2007 and trends that develop will be monitored.

Families also report concern regarding transition services available from the Department of Rehabilitative Services (DRS) because of the current Order of Selection under which DRS is operating. Order of Selection limits services to those persons categorized under the federal Rehabilitation Act as having the "most significant" disability(ies). Students who do not meet these criteria cannot receive vocational rehabilitation services that they may need in order to be successful in postsecondary employment or higher education.

6. **Disparity in Student Achievement:** Achievement differences between students with and without disabilities continue to be an issue as evidenced through VDOE statistics and as cited in public comment to VBPD and to the SSEAC. In terms of academic performance, the following table provides comparative passing rates for the last three school years on state assessments as part of the annual School Report Card.

#### ACADEMIC ACHIEVEMENT IN STATE ASSESSMENT TESTS, 2004–2007

	<u>English</u>			<u>Math</u>			<u>Science</u>		
	<u>2004–05</u>	<u>2005–06</u>	<u>2006–07</u>	<u>2004–05</u>	<u>2005–06</u>	<u>2006–07</u>	<u>2004–05</u>	<u>2005–06</u>	<u>2006–07</u>
<b>All Students</b>	81%	84%	85%	84%	76%	80%	84%	85%	88%
<b>Students with Disabilities</b>	56%	64%	62%	61%	53%	58%	64%	65%	67%

As the data show, performance on state assessments for all students (which includes students with disabilities) was significantly higher than the scores for the subset of students with disabilities; and was the lowest of all the student subsets including those identified as “disadvantaged and students who have limited English proficiency.” Scores did rise slightly for students with disabilities in FY 2006–2007 compared with the previous years, but remained at least 20 percent below all students. Rigorous targets for improvement and corresponding strategies have been set forth at the state level, including statewide training and technical assistance, online tools and tutorials, and provision of instructional resources and pilot demonstration programs using best practices from other states.

7. **Disparity in Student Graduation Rates:** A significant difference remains between graduation rates among students with and without disabilities and it also bears noting that graduation for all students, with and without disabilities, has decreased over the last 3 school years. Families report through public comment that they are not informed adequately about what being in a separate (non-SOL) curriculum track means and are then shocked that their child can’t get a Standard diploma. The graduation rate (calculated as those receiving an Advanced Studies or Standard diploma) for students with disabilities has remained far below that of all students:

<b>Graduation Rates</b>	<b>All Students</b>	<b>Students with Disabilities</b>
<b>2003–2004</b>	90.5%	52.6%
<b>2004–2005</b>	90.3%	51.5%
<b>2005–2006</b>	85.2%	48.6%
<b>2006–2007</b>	Not yet available	43%

Beginning with the 2006–2007 school year, Virginia was required to use the No Child Left Behind (NCLB) graduation rate calculation, which uses a different methodology than in the past. Had that methodology been used in the 2005–2006 school year, the graduation rate for all students would have been 79 percent and for students with disabilities 42 percent.

The disparity in dropout rates between students with and without disabilities is much less. The 2005–2006 state target of a 1.93 percent dropout rate for students with disabilities was not met, nor was the 2006–2007 state target of 1.91 percent. It is positive, however that these data are now being compiled and can be tracked.

#### **Dropout Rates—Grades 7–12**

	<b>All Students</b>	<b>Students with Disabilities</b>
<b>2004–2005</b>	1.86%	1.96%
<b>2005–2006</b>	1.89%	2.2%
<b>2006–2007</b>	1.86%	2.3%

8. **Need for Increased Numbers of Appropriately Trained Qualified Staff:** Ensuring student achievement, instruction in the least-restrictive environment, and access to the general curriculum are directly related to having adequate numbers of and appropriately and effectively trained staff members. The State Special Education Advisory Committee (SSEAC) has cited concern over the last several years regarding the number of special

education teachers leaving the field and the high number of teaching staff members with conditional licensure. Inadequate staff training and experience continue to be cited by families as areas of concern relating to general and special education staff members as well as paraprofessionals, related-services personnel, sign language interpreters, and bus drivers.

Those making comments report a lack of collaborative teaching experience, inadequate coursework in special education and/or disabilities for general education teachers, inadequate training and knowledge regarding vocational services and options, curriculum modifications, use of assistive technology, and a reluctance of some school divisions to take advantage of training resources available to them such as the Training and Technical Assistance Centers (TTACs). Concerns are particularly high with respect to meeting the needs of students with disabilities such as autism and brain injury in which specialized training and experience are essential to ensuring that these students receive a free appropriate public education.

Teachers in Virginia public schools are considered to be fully qualified for their position when holding a current five-year, renewable license with endorsements in the area for the position assigned or other appropriate credentials. Concerns expressed through public comment to the SSEAC included challenges in preparing special education teachers to meet the “highly qualified” standard under No Child Left Behind and IDEA 2004 with a fear that the standard will result in less, rather than more qualified instructional staff members.

- 9. Inadequate Parent Involvement and Access to Information:** Public comment provided to the Virginia Board for People with Disabilities (VBPD) indicates that even when parents are informed, they often do not understand the complex education laws pertaining to their child with a disability, and they are often unprepared and ill-equipped to advocate for their child’s interests. Parents report feeling overwhelmed with the amount of information and paperwork involved in the special education process and believe they are not provided sufficient information about options and services for which their child may be eligible. This is particularly true when making decisions on assessment and diploma options that affect their child’s future. If parents feel unprepared for their involvement in their child’s education, the students themselves are likely even less informed or prepared to participate in decisions about their future.

Parents also desire and need information on other services, supports, and community resources that may be available to them. Schools are the most natural environment through which parents could receive information on home- and community-based waivers, community service boards or other locally available services, benefits, and benefits planning for postsecondary life. Unfortunately, at this time, many school staff members are not knowledgeable about programs and services outside of the education system, and thus a prime opportunity to educate and inform parents is lost. The Virginia Department of Education (VDOE) has developed and mailed a survey instrument designed to elicit information on whether schools facilitated parent involvement as a means of improving services and results for children with disabilities; results are pending.

10. **Inadequate Access to and Use of Assistive Technology:** Appropriate access to assistive technology in school divisions is an issue cited by families in public comment and also raised before the State Special Education Advisory Committee (SSEAC). Families report state that even when appropriate technology is included in their child’s IEP, the technology is often (1) not available to their child; or (2) the teacher or teachers are not trained in how to use the technology; (3) the child is not allowed to bring the technology home even if it is needed for educational purposes in the home environment; or (4) technology is outdated. Access to needed technology after graduation can also be a problem. While some students may be able to obtain technology under Medicaid or through vocational rehabilitation services, some will not have a payment source and may have to give up a critical support. Use of technology, including state-of-the-art communication devices, can make the difference between school success and failure.
11. **Disproportionate Representation in Special Education Placement:** Past legislative studies and Virginia Department of Education (VDOE) data have found that African American students are generally disproportionately represented in special education when compared to the general population, specifically in the VDOE special education disability classifications of mental retardation (intellectual disability), emotional disturbance, and developmental delay. In 2003–2004, VDOE data noted that African American students spend a greater portion of their day in special education programs. As a result, early academic remediation was implemented as a strategy to address this issue. As noted in the Monitoring and Evaluation section of this chapter, the federal Office of Special Education Programs (OSEP) has implemented a new federal indicator in this area.

VDOE’s 2005–2006 data found that 6 percent of school divisions had significant disproportionality and 9 percent had some measure of inappropriate identification. For the 2006–2007 school year, due in part to an altered OSEP methodology for analyzing disproportionate representation discussed earlier, Virginia met the Indicator 9 and 10 targets of 0 percent. Even though the targets were met, VDOE reports in the *Part B Annual Performance Report for 2006–2007* that it continues to provide training and technical assistance to all school divisions regarding these issues. School divisions will continue to review individual student records as the source for providing data to VDOE for the indicators related to disproportionate representation and VDOE will continue to comply with OSEP requirements and upcoming guidance. Because of the requirements have changed and may change further, performance on this indicator bears monitoring.

12. **Challenges in Assessment of and Accountability for Students Receiving Special Education Services:** Families continue to be concerned about their children’s participation in the state’s accountability system and the impact of participation, or lack there of, on diploma options, as noted above. Public comments noted concern that some school divisions are “blaming” students with disabilities for low Standards of Learning (SOL) scores and higher costs and parents are fearful that this will result in increased segregation of students with disabilities. Parents are also worried that because of the focus on “high stakes testing” school divisions may increasingly attempt to steer parents into having their children participate in the Virginia Alternate Assessment Program (VAAP), which is available to

students who are not in the SOL curriculum. There is a federal limit to the number of students who can take the alternate assessment (1 percent); therefore, it is unclear whether the concern expressed is valid. It does, however, bear monitoring.

- 13. Inadequate Services to Children with Vision Impairments:** According to the Department for the Blind and Vision Impaired (DBVI), children with visual impairments do not always receive the age appropriate orientation and mobility services that they need to travel independently, confidently, and safely in their homes, schools, and communities. As noted in the chapter detail, the level of state funds to support public school programs for students with visual impairment is significantly lower than the support received for other teachers of students with other disabilities. This inequity exists because teachers of these students are funded through the Department for the Blind and Vision Impaired (DBVI) rather than the Virginia Department of Education's (VDOE) Standards of Quality (SOQ) funding formula. In addition, DBVI's funding to support teacher salaries has remained flat since 1991. Special education teachers of students with visual impairments are the only such teachers who do not have a caseload maximum. This results in much higher caseloads for some instructors of vision-impaired students.
- 14. Lack of Physical Accessibility of Some Public Schools:** Fifteen years after the Americans with Disabilities Act, there are numerous public schools in Virginia that are still not physically accessible. In the City of Richmond, litigation was filed with respect to this issue. Although the law does not require every school to meet ADA guidelines (depending on date of construction and undue burden standards), the availability of accessible school buildings should be reviewed by every community. The lack, or limited availability, of accessible buildings directly and negatively affects school division ability to meet both LRE requirements and the mandate that students should attend the school they would ordinarily attend unless their IEP dictates otherwise. Students with disabilities should be welcome and able to gain access to all public schools in the Commonwealth and should not be separated from their siblings, neighbors, and friends as a result of physical access issues.
- 15. Challenges of Local Advisory Committees (LACs):** In 2005, the Virginia Board for People with Disabilities (VBPD) awarded a grant to the Partnership for People with Disabilities (PPD) and Virginia Department of Education (VDOE). The grant provided training to current and potential LAC members in all eight Superintendent's regions. VDOE contributed substantial resources to this initiative. Although the training received positive reviews, a guide was developed, and VDOE has committed additional funds to continue training LACs, it is unclear whether any systemic change in the operation or outcomes of LACs has resulted. Public comment provided to the Board in 2007 notes that attendance at LAC meetings remains sporadic and that membership remains static, lacking an infusion of new members. In addition, public comment notes that even when LACs are active, they have little influence over local school board decisions. In a recent development, the draft special education regulations allow for school division personnel to serve as members of the LACs. In the past school division staff members could only serve as consultants. The VDOE staff reports that this change was made so that school division staff members who also happened to be parents of students with disabilities would not be excluded from LAC participation.

VBPD is concerned about this potential change in regulation. Public comment over the years indicates that there has been significant interference by local school division staff members in LAC activities; part of the VBPD-sponsored training was aimed at educating school division staff members about their proper role as “consultants.” It is a clear conflict of interest for school staff members to serve on a committee that advises their school board and could be highly intimidating to other committee members.

## **Board Recommendations for Education Services**

To ensure improved access to the general curriculum, education in the least-restrictive environment, and improved achievement by students with disabilities, including those with significant disabilities, the Virginia Board for People with Disabilities (VBPD) recommends the following, much of which remains unchanged since the *2006 Biennial Assessment*.

- 1. Provide Increased and Improved Training to Prepare Teachers to Effectively Teach Students with Disabilities:** VBPD recommends that Virginia require that all of its public institutions of higher education mandate special education coursework for students enrolled in teacher training programs. This should include specific coursework in disabilities as well as how to work with students served under an Individualized Education Program (IEP) in the general education classroom. Strategies that should be taught include but are not limited to: collaboration, instructional and learning strategies, and effective schoolwide discipline. In addition, in-service training programs should be developed to ensure that general education and special education teachers receive ongoing continuing training and education in best practices in education of students with complex needs.
- 2. Analyze Student Outcomes as Related to Least Restrictive Environment (LRE), Student Achievement, and Graduation Rates:** VBPD recommends annual trend analysis of the data now being collected regarding the target areas above. In particular, newly available data (since 2005) regarding time spent by children with disabilities outside of the regular education classroom will likely reveal important trends. With LRE a continuing concern for families, these data will enable the Virginia Department of Education (VDOE) to determine whether individual school divisions are complying with LRE requirements. It will also enable VDOE to target its training and technical assistance activities and showcase school divisions that implement best practices and high expectations of students. VDOE should also implement enforcement actions for school divisions that have disproportionate numbers of students educated in more restrictive environments.

Ongoing analysis and public reporting of student achievement and graduation rates should also occur on an annual basis. The State School Report Card is an excellent tool but many of the federally required reports are challenging in format and content, making it difficult for a layperson to understand the data and its implications.

- 3. Ensure Access to the General Curriculum/Standards of Learning:** VBPD recommends that VDOE continue to provide technical assistance and guidance to local school divisions to ensure that all students with disabilities have access to the general curriculum and implement appropriate technical assistance and enforcement activities. It should be a priority of every

school division to ensure that students are properly assessed for technology needs that will enable them to have appropriate access to the general curriculum. Families should be provided with information on at least an annual basis of their child's right to access to the general curriculum and the effect that choices made with respect to participation in the Standards of Learning (SOL) will have on the student's future. This should include annual information on diploma options and assessment choices and a report on the child's current status with respect to whether he or she is on track to receive a Standard, Advanced, or Modified diploma. Although information provided by VDOE clearly stipulates that parents and students must be informed of the consequences of all decisions related to assessments, it is unclear whether all families understand the ramifications of the decisions that they are making on behalf of the student. While VDOE notes that it is providing Web resources, coordinated statewide training, and workshops for middle and high school administrators, in partnership with the Virginia Association of Secondary School Principals, it is just as important to provide this information in a clear, understandable format to families and students.

4. **Maintain State Regulatory Protections for Families:** VBPD recommends that the Board of Education reverse its position on the removal of certain critical regulatory provisions in the State Special Education Regulations. Virginia's state regulatory protections have historically exceeded federal protections in a number of areas, including consent. Virginia can be proud of this and should continue these important student protections. VBPD opposes the removal of any regulatory provisions designed to protect students and families. VBPD supports maintaining the age at which transition services are mandated at 14 and appreciates that the Board of Education has maintained this age threshold.
5. **Ensure Appropriate Services to Students with Autism:** VBPD supports current statewide efforts underway not just in education but also throughout the disability services system to develop a system of services and supports for persons with Autism Spectrum Disorders across the life span. The need is particularly urgent in the area of education where there is great variability in the services provided to students with autism depending on where the student resides, the wealth of the locality, and the strength of parent advocacy groups. VBPD recommends that Virginia examine the work of other states that have developed a statewide system that ensures that all students have access to effective, appropriate services. While the Board does not support any specific model of intervention, states like North Carolina can be used as models for best practices in statewide service delivery. Numerous interventions are available, many of which have only anecdotal evidence of efficacy but no scientific research establishing them as effective interventions. As noted in the Early Intervention section, as therapies and interventions are developed, it is critical that the Commonwealth keep up with effective, evidence-based practices in order to be responsible and prudent with public dollars and to ensure that therapies and interventions paid for by taxpayers have the best outcomes for students.
6. **Increase Pool of Providers for Students with Vision and Hearing Disabilities:** VBPD recommends (as noted in 2006) that Virginia reestablish an approved preparation program for teachers of students with vision impairment (TVI) at one of its colleges or universities. This

will help school divisions fill their vacant TVI positions and will expand the number of TVI teachers in Virginia. Middle and secondary schools in Virginia should be strongly encouraged to offer American Sign Language (ASL) as part of foreign language offerings; and, in addition, public institutions of higher education should be encouraged to accept ASL as a foreign language for purposes of college admission.

7. **Evaluate the Impact of Technical Assistance Efforts on Local Practice:** The Virginia Department of Education (VDOE) has numerous initiatives in place that are designed to improve student academic achievement, instructional quality, graduation rates, transition services, quality and quantity of providers, etc. Innumerable technical assistance documents have been developed and training through the Training and Technical Assistance Centers (TTACs), among other resources, are available. VBPD recommends that VDOE examine and address the apparent gap between the efforts being done at the state level and the limited or lack of implementation at the local level within the constraints of a system in which local control is a principal tenet.

## IV. Community Living Supports

### Areas of Concern about Community Living Supports

The chapter detail provides information on services and supports available to persons with disabilities through a variety of agencies and programs. As noted in the introduction, the content is not all-inclusive, nor is the information about each program and service completely comprehensive. For additional, more-detailed information, the reader can refer to the agency and program reports available on the Internet or in the resource list at the end of the chapter. Cited throughout the chapter are important statistical data regarding program activities and performance indicators. The chapter detail also provides information on areas in which the system and services have improved and describes improvement activities and outcomes. Section G focuses on the specific areas in which further improvements may be needed to move the system forward and ensure that the needs of eligible infants and toddlers with disabilities throughout the Commonwealth are met. The Virginia Board for People with Disabilities (VBPD) identified the issues and concerns below through a variety of mechanisms, including: (1) review and analysis of the numerous source documents referenced within and listed at the end of this chapter, (2) public comment received via VBPD's six public forums held throughout the state in the spring of 2007, and (3) written comment and information provided and verified by state agencies in their reviews. The issues below are not all-inclusive, but represent those that the Board has identified as important to systems improvement.

Community living supports are paramount for VBPD because community inclusion is the predominant focus of the Developmental Disabilities and Bill of Rights Act of 2000 under which the Board is authorized and funded. VBPD has invested hundreds of thousands of dollars and has partnered with state and local agencies as well as private organizations to develop and/or facilitate creative community living options and services and supports for people with developmental disabilities. As the issues below demonstrate, however, much more work is needed to move the system forward.

- 1. Fragmentation of Disability Services System:** As described in the *2006 Biennial Assessment* and this chapter, service fragmentation remains problematic. Services to persons with disabilities continue to be administered in highly compartmentalized systems at both the state and local levels. There is no overarching, person-centered or life-span organization in the state system designated for persons with developmental and other disabilities. Service "silos" exist, in part, because many state agencies have a specific disability constituency determined by diagnosis. Some agencies serve the entire spectrum of disability diagnoses, but have a narrow service mandate, e.g., provision of vocational rehabilitation services. In addition, state agencies that do not have a disability focus often lack information, knowledge, and experience with regard to the needs of persons with disabilities, and do not include them in their planning. While the system remains unchanged at present, there is a growing recognition by policymakers that Virginia's historical definitions of disability and provision of services within specific service silos based on disability or type of service is a contributor to service and planning fragmentation. As noted in this chapter, a growing number of positive initiatives are underway to improve comprehensive, integrated planning for persons

with disabilities. Prominent examples include, but are not limited to, the Systems Transformation Grant, the Money Follows the Person initiative, and recent studies such as the MR Waiver Systems Study and the efforts conducted by the Joint Commission on Health Care's Workgroup on Autism.

2. **Lack of a Developmental Disabilities "System":** As reported in 2006 and unchanged at present, unlike individuals with a diagnosis of intellectual disability (mental retardation), people with developmental disabilities do not have a "home," i.e., a dedicated funding stream and service system to meet their needs. Virginia, unlike other states that 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 those with developmental disabilities. Despite implementation of the Developmental Disabilities (DD) Waiver and Department of Mental Health, Mental Retardation and Substance Abuse (DMHMRSAS) training efforts on person-centered planning, the current service system still lacks a person-centered focus and a life-span design regarding persons with developmental disabilities who do not have a concurrent diagnosis of intellectual disability. Thus, 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.

In response to the 2007 passage of House Resolution No. 60, the Joint Commission on Health Care Behavioral Subcommittee began to study the issue of a "home" for Autism. This discussion was expanded to Developmental Disabilities as a whole. A workgroup was formed that included advocates and family members as well as representatives from various state and local agencies. The result was budget language by the Joint Commission asking the Secretary of Health and Human Resources to develop an implementation plan to determine the state agency that should be responsible for autism services or developmental disability services as a whole. The Governor's budget for the 2008–2010 Biennium has proposed a position at DMHMRSAS to address autism services. Another proposed legislative study seeks to examine best practices in autism as well as training for law enforcement personnel.

3. **Institutional Bias of Disability Services System:** Virginia continues to spend a disproportionate amount of funding on institutional versus community-based services and has lagged behind most of the rest of the nation in its funding for community services. Virginia continues to be ranked among the lowest of all the states in community Medicaid expenditures across several indicators, although we have moved from 48th in FY 2005 to 46th in FY 2007. Virginia is behind many other states in the development of critical community-based living and support options for persons with developmental disabilities, enabling few real choices for persons who would choose to live in the community if services and supports were available.

The aging and condition of state Training Centers also remains a major concern, since the "youngest" facility is more than 30 years old and two others have substantially older buildings in use. The *2007 Study of the MR Service System* proposes a major state commitment for funding of MR Waivers and community services, including residential

options, over the next four biennia; it also continues a commitment, however, to renovate the aging facilities. Over time, renovation costs at these and other state facilities are likely to increase. Given the finite nature of state revenue, renovations will have a negative impact on the moneys available for community services.

In addition to concerns expressed by parents whose children reside in the Training Centers, as elsewhere, the emphasis on maintaining institutions continues to be driven, in part, by the economic and political concerns that eliminating the state Training Centers would damage the economy of the community in which each is located. The more likely reality is that jobs will continue, but with a change in the location of services. Moreover, building community infrastructure will result in expanded employment opportunities for localities statewide. While the Commonwealth's philosophy and intent is to develop community infrastructure and supports, significant political support is needed to refocus Virginia's effort on community versus institutional infrastructure.

4. **Continued Growth of MR and DD Home and Community Based (HCB) Waiver Waiting Lists:** The Medicaid HCB Waiver has become the principal, if not the only, source of funding for community supports for many families. Incremental yearly funding increases for Waiver slots continue to be the norm, while need and the waiting lists grow. DMHMRSAS estimates that the wait list for Mental Retardation (MR) Waiver has grown by one person per day since FY 2004; and found that the average length of time on the MR Waiver Waiting List is 28 months, but for some individuals it is as high as 7 years. Neither the MR nor Developmental Disabilities (DD) Waiver Wait lists may reflect true need, however. While it is clearly not the policy of DMHMRSAS, the Board frequently hears comments from families discouraged by local agencies from applying for a waiver slot because of the long wait; others may simply be unaware of potential eligibility for Waiver services.

An additional concern regarding the MR Waiver Wait List issue is that persons residing in nursing facilities and small ICFs-MR cannot be placed on the Urgent Waiting List and are not listed on the nonurgent list, because their health, safety, and welfare needs continue to be met while institutionalized. At least one advocacy organization opposes the allocation of adding facility residents to the Urgent Waiting List since it will increase that list's size and, according to the organization's public comment, place facility and community residents in competition with one another for limited slots. VBPD agrees that the solution is adequate funding of Waiver slots for those on the waiting list. Under the current system, however, persons in institutions have little hope of ever living in the community with the needed services and supports that would be provided under the MR Waiver. A review of the outcome of the Money Follows the Person demonstration initiative will prove extremely helpful in determining how best to proceed in this area.

5. **Growth of Non-Waiver Program Wait Lists:** While the political and advocacy focus is primarily on the Home and Community Based (HCB) Waiver Waiting Lists, those lists also exist for other community-based services. Examples of programs with waiting lists include, but are not limited to: the Community Rehabilitation Case Management Program and the Personal Assistance Services (PAS) Program, both administered by the Department of

Rehabilitative Services. Sufficient funding for these programs would provide critical community supports for persons who are on a waiver waiting list or who are not eligible for a waiver, but require a level of support to live successfully in the community. It should be noted that some programs do not maintain waiting lists, making it difficult to assess and plan for actual funding and program needs.

**6. Need to Examine Home and Community Based (HCB) Waiver Waiting List**

**Administration/Slot Allocation:** Administration of HCB Waiver Waiting Lists has become an issue of considerable controversy. The Developmental Disabilities (DD) Waiver has statewide administration with emergency slots available. In its *2006 Biennial Assessment*, the Virginia Board for People with Disabilities (VBPD) recommended statewide administration of the Mental Retardation (MR) Waiver Waiting Lists rather than the current system of local determination of MR Waiver slot distribution. This 2006 VBPD recommendation was made to address concerns regarding variation between localities in a person's access to and waiting period for the MR Waiver and widely divergent local practices; and ensure that the limited MR Waiver slots went to those with the most urgent needs first, regardless of the locality in which they resided. The VBPD 2006 recommendation provoked considerable opposition from the Virginia Association of Community Services Boards (VACSB), from the Arc of Northern Virginia, and the Arc of Virginia. Public comment from these entities to the Board in 2007 posited that the current allocation system works well, and that localities are best able to determine the needs of their residents.

There is definitely strong disagreement among advocates on this issue. VBPD believes, however, that no issue should be "off limits" and that issues of fairness and equity across the state remain. There should be, and must continue to be, open dialogue on this and other controversial issues associated with providing the best services possible to mutual consumers.

**7. Lack of Choice in Case Management for MR Waiver Recipients:** In its *2006 Biennial Assessment*, the Board brought forth the issue of ensuring choice under all HCB Waivers for all services, including case management. VBPD noted that the difference in choice under the Developmental Disabilities (DD) Waiver versus the Mental Retardation (MR) Waiver represents an equity issue for individuals receiving services under the MR Waiver who do not have the opportunity to choose a case management provider from outside of the Community Services Board (CSB) system.

The VBPD recommendation for full choice of case management providers for MR Waiver recipients resulted in extensive dialogue and significant opposition from several entities, including the Virginia Association of Community Services Boards, the Arc of Northern Virginia, and the Arc of Virginia. On the other side of the issue are the Centers for Independent Living and Autism/DD advocates statewide who believe that choice in case management is an essential protection for families and a right under the HCB Waiver system. In addition to public comment received by VBPD, the issue of choice in case management was a source of considerable discussion at the 2007 Joint Commission on Health Care's

Workgroup on Autism, during which DD and Autism advocates and family members opposed Waiver or service consolidation unless choice was maintained. VBPD respects the differing opinions on the issue but believes it is a disservice not to bring forth issues in which further examination is both desirable and important.

8. **Concern over Organizational Conflict of Interest:** In its *2006 Biennial Assessment*, the Virginia Board for People with Disabilities (VBPD) reported that public comment in a variety of arenas indicated that the multiple roles some community service boards (CSBs) have for planning, screening, referring, providing, funding, and overseeing services can be problematic with potential bias in service provision or less rigorous oversight. Families have reported that they believe their family members are automatically steered to the services offered by their CSB. Other family members indicate satisfaction with CSB services and processes. Many individuals throughout the Commonwealth are clearly served very well through the CSB system. Regardless of the excellent intentions and work of CSBs' Board members and staff, however, there is an inherent systemic conflict of interest whenever a single entity (whether private or public) is responsible for the multiple roles of determining initial and annual eligibility, providing case management, service planning, service delivery, service funding, and service oversight.
9. **Lack of Funding Stream for Individuals not Eligible for Home and Community Based (HCB) Waivers:** As addressed in the 2007 Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) *Study of the MR Services System in Virginia*, because of restrictive eligibility criteria (i.e., meeting ICF-MR eligibility), many individuals with developmental disabilities including, but not limited to, those with intellectual disabilities, are not eligible for HCB Waiver services and receive few or no community supports. The lack of a funding stream or of program-support options for these individuals is a serious gap in the service system that requires further study, analysis, and action. VBPD supports the DMHMRSAS study recommendation that General Fund dollars be committed to provide services and supports for these individuals.
10. **Inadequate Funding for Centers for Independent Living (CILs):** As entities required by federal statute to be both multidisability and peer-directed or -operated, Centers for Independent Living (CILs) are key resources for persons with disabilities residing in communities. Virginia has been more successful than other states in expanding CIL services and obtaining additional state funding for CILs. CIL activity is still limited, however, by relatively low funding levels (funding remains below the recommended national base [currently, \$250,000] for seven CILs or satellites) and gaps in geographic availability of CIL services, with some parts of the state completely unserved. Since FY 2005, new state funding has been provided to support CILs and two new satellite CIL centers opened in 2007. These increases are positive but have not met the demand as identified by the CIL budget requests and public testimony. Core and other services offered by Centers for Independent Living provide critical assistance to persons with disabilities and are strongly focused on consumer direction and self-determination.

**11. Inadequate Availability of Qualified Providers:** The availability of adequate numbers of qualified providers continues to exist. Demand for qualified, reliable direct care staff members continues to outstrip their availability. Low pay and reimbursement rates, lack of employee benefits, and a cumbersome payment system result in low numbers of individuals willing to enter or remain in the field as well as high rates of turnover between providers and recipients of the services. There is also marked disparity in regional availability of providers with Northern Virginia having fewer challenges than more rural areas of the state, which have severe shortages. A noted fiscal barrier for residential providers is the lack of funding for “general supervision.” A lack of respite providers was also cited as a key issue during the Virginia Board for People with Disabilities (VBPD) 2007 public comment events.

In 2007, the Governor’s Health Reform Task Force Final Report *Roadmap for Virginia’s Health* addressed numerous issues with respect to quality of care, access to care, and long-term care, among other related issues. The recommendation concerning access to a “seamless coordinated system of information and decision-making tools” and increasing the “availability and scope of integral services for seniors and person with disabilities” are extensive and are supported by VBPD. This report also contains an excellent description of the challenges of the direct care workforce and a number of recommendations regarding the nursing and direct support workforce that VBPD also supports.

**12. Low and Inconsistent Home and Community Based (HCB) Waiver Reimbursement**

**Rates:** Low provider reimbursement rates continue to be an issue that inhibits both the growth of community-based services and supports and the development of new providers and services. In particular, rates for personal care, respite, and skilled nursing services are too low to attract and maintain providers. Annual cost-of-living increases are needed but are not given to providers or to the HCB Medicaid Waivers. While some providers devote all or a portion of rate increases to direct salary increases for the staff, others utilize rate increases to cover increased administrative costs. While VBPD understands the need to cover the costs of operation, the argument for rate increases has historically been to hire and maintain a high-quality staff. It is logical, then, that a portion of any rate increase should be used for this purpose.

Another challenge is that rates are not tied to the level or intensity of support needs. Thus providers may not be willing to work with individuals who have more complex needs, particularly behavioral challenges. This also makes it challenging for persons with significant disabilities to “age in place.” A third challenge has been the variability of reimbursement rates by different agencies for the same service. As reported in the *2006 Biennial Assessment*, the reimbursement rate for supported employment paid by the Department of Rehabilitative Services (DRS) was significantly higher than that paid for this service under Home and Community Based Waivers. The 2008 General Assembly passed budget language that will remedy this longstanding issue as of July 1, 2008.

There was an attempt to pass budget language to remedy the disparity in case management rates paid under MR versus the DD Waiver but the language did not pass. The responsibilities are nearly identical, with the exception of one additional responsibility for

DD case managers, but the DD case management is paid at a significantly lower rate. It has been reported that the additional money for case management can be or is being used by CSBs to provide other essential services to its consumers. VBPD does not want to see any loss of funds that would affect consumers; however, funds should be used for the purpose they were allocated. The same service should not be compensated at significantly higher rates so that it can fund other services. There should be a transparent budget that reflects where the funding is going.

13. **Low Personal Maintenance Allowance (PMA):** The state's Home and Community Based (HCB) Waivers require some waiver recipients to contribute to the cost of the covered services. These fees, or "patient pay" (i.e., co-pay) amounts, are determined by DSS by formula. The PMA, however, is not consistent across Waivers (165 percent of SSI, \$1,051.05 in 2008) for all but the AIDS Waiver, which is much higher at 300 percent of SSI (\$1,911 in 2008). In all but the AIDS Waiver, the PMA is insufficient to support successful community living. Individuals with low resources are often unable to pay the required patient pay and meet their personal expenses for shelter, food, and clothing, especially in high income/expense areas such as Northern Virginia. In 2006 the Joint Legislative and Audit Review Commission (JLARC) reported provider feedback that the required patient pay "can be a major barrier to their ability to receive waiver services." Moreover, JLARC pointed out: "Virginia ranks in the bottom ten states in this allowance."
14. **Inadequate Services for Persons with Brain Injury:** In its 2006 *Strategic Plan*, DRS noted that the demand for brain injury and spinal cord injury services in Virginia continued to outweigh available resources. According to the 2007 JLARC study, *Access to State-Funded Brain Injury Services*, although the level of state funding for brain injury services has increased by more than \$2.5 million since FY 2001, some parts of the state had few or inadequate services for brain injury, such as adequate case management, clubhouse or day programs, specialized inpatient/residential facilities for persons with brain injury and severe neurobehavioral disorders, rehabilitation services for cognitive impairments, supportive or transitional housing, and transportation. Most private insurance plans were found to offer limited, if any, coverage for brain injury services. JLARC noted that lack of community services would put persons with brain injury at risk of placement in nursing homes or other long-term care institutions.
15. **Inadequate Access to Quality Interpreter Services for Persons Who Are Deaf, Hard of Hearing, or DeafBlind:** Concerns were raised at the Board's 2007 public comment events that access to appropriate interpreter services for persons is inadequate statewide. This is true for students with disabilities who require interpreter services in the public school system as well as for children and adults who require these services in other arenas. Lack of access was noted as particularly problematic in colleges and universities, public mental health and substance abuse services, and in public meetings. It is reported by the Virginia Department for the Deaf and Hard of Hearing (DDHH) that it is insufficient just to have access to an interpreter. The interpreter must have the skill level necessary to convey the messages of both the person who is deaf and the person who is hearing. Qualified interpreters are those who have demonstrated skill levels in a variety of situations and, preferably, who have

achieved a Virginia Quality Assurance Screening Level II or higher or national certification. A key factor influencing the availability of qualified interpreters has been the growth of Video Relay Services (VRS). VRS uses qualified sign language interpreters to convey information in lieu of traditional text-based telecommunication relay services, such as Virginia Relay. VRS has been able to offer excellent pay and benefits, steady hours, and flexible qualifying credentials to encourage interpreters who have been working in community settings to become full-time VRS interpreters. As VRS and Video Remote interpreting (another video-based service employment interpreter) continues to grow in popularity, the availability of traditional on-site freelance interpreters will continue to diminish. Other factors that contribute to the dearth of qualified interpreters include limited success in recruitment, the limited availability of formal training programs and qualified instructors, and the time needed for a new interpreter to become proficient. Demand and need for these services exceeds supply and the service is costly.

**16. Services to Children via the Comprehensive Services Act (CSA):** The intent of the Comprehensive Services Act (CSA) has not lived up to its promise to “create a collaborative system of services and funding that is child-centered, family focused and community based when addressing the strengths and needs of troubled and at risk youth and their families.” The needs of many children continue to be unmet as the result of various factors: lack of available services in some communities, insufficient coordination of services between agencies, and the fact that parents of some children have had to relinquish custody of those children in order for them to receive services. In response to House Joint Resolution Number 60 in 2006, the Joint Legislative and Audit Review Commission (JLARC) conducted an extensive study, *Evaluation of Children’s Residential Services Delivered through the Comprehensive Services Act*. The final JLARC report released in 2007 made a broad range of recommendations to improve availability of needed community services to children and their families, to improve outcomes, and to strengthen oversight protections. The Board defers to the expertise of JLARC with respect to the issues identified and the recommendations made but believes that it should acknowledge the significant challenges faced by children and families served under this system. For his 2008–2010 budget, Governor Kaine proposed financial incentives for use of community-based services rather than congregate care, higher maintenance payments to foster families, and implementation of a data tool with which to track treatment outcomes.

**17. Inadequate Access to Assistive Technology (AT):** Access to assistive technology (AT) can be a critical factor for an individual with a disability to live successfully in the community, to be gainfully employed, and to live a full, productive life. Federal funding for this area has been static; and certain policies and practices themselves are barriers to AT access. With the changes in the federal Assistive Technology Act in 2004, state AT systems must focus 70 percent of funding on AT recycling. Many Disability Services Boards (DSBs) identify access to assistive technology as a challenge in their assessment of local/jurisdictional needs. These needs include: AT assessments and training, access to devices for those who cannot purchase what they need, repair of devices and equipment owned by individuals, and a lack of public awareness of AT. Many of the services offered by the Virginia Assistive Technology System (VATS)—such as information/referral, training, and technical

assistance—either are not reimbursable or generate inadequate reimbursement. In addition, as mentioned earlier, individuals receiving AT under Home and Community Based Waivers receive one-time training in the use of the devices but many require and are unable to obtain ongoing training for more complex ATs.

**18. Need for Individualized Budgeting and Increased Consumer Direction:** Service systems that are progressive promote the concept that self-determination is a right of every citizen and demonstrate this fundamental right by offering options such as consumer-directed services and individualized budgeting to the greatest extent possible. Consumer-directed options are growing in Virginia but are still available inconsistently within the array of services covered by Virginia's Home and Community Based (HCB) Waivers. Among families and providers, there appears to still be a fairly widespread lack of understanding about the meaning of consumer- or family-directed services, self-determination, and person-centered practices. This lack of understanding often results in guardians of individuals with disabilities not believing that the person for whom they have decision-making authority is capable of making any choices and decisions of their own. To the maximum extent possible, an individual's decision-making authority and options should be based on each individual's strengths, support needs, likes, preferences, and relationships. This includes individuals who are not verbal or who may need assistance to communicate. Individuals with disabilities and their families need appropriate information and training to choose and direct their own services and to understand that within consumer direction there is a continuum of options. Individualized budgeting can support and enhance increased consumer direction and is also a goal of the Systems Transformation Grant (STG) currently underway with the Department of Medical Assistance Services as the lead agency. An individualized budget would enable persons with disabilities to have a flexible pool of funds available to them and for which they would be accountable. Individualized budgets would greatly enhance consumer direction of services, and we look forward to its continued evolution and implementation in Virginia.

**19. Inadequate Availability and Use of Alternatives to Guardianship:** Inadequate knowledge about and use of alternatives to guardianship for persons with disabilities continues to be a challenge. Often court-ordered guardianship is executed and the appointed guardian may or may not know the individual for whom he or she is providing decision-making services. With respect to persons residing in state Training Centers, guardians and authorized representatives may make uninformed decisions or decisions that would be inconsistent with the individual's choice. Court-appointed guardians are often unaware of the availability of services and supports that may be obtainable. Students with disabilities who reach the age of majority may lose their rights because parents may seek a determination of capacity in order to obtain guardianship for their children with disabilities. Some parents and school staff members may lack knowledge of less intrusive alternatives, such as limited guardianship or power of attorney. It is clear that there are still many obstacles to maximizing decision-making for persons with disabilities and that many families and authorized representatives continue to obtain full guardianships as a first rather than a last resort. It is very difficult to reverse a court-ordered guardianship once it has been instituted and less restrictive alternatives should be the norm, not the exception.

**20. Enhance Quality of Life in and Oversight of Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) Licensed Community**

**Living Settings:** There is legitimate concern regarding the need to ensure that people with disabilities living in congregate settings in the community enjoy a high quality of life and are free from abuse and neglect. The 2007 *Study of the MR Services System* found that individuals who chose state Training Center placement for their family member most often cited permanence, safety, and welfare as key reasons for their choice, feeling that state facilities are better regulated. Many challenges exist with respect to ensuring good quality and safety but two that stand out are regulations that are not consistent with the values associated with person-centered practices (PCP) and capacity issues within the DMHMRSAS Office of Licensure.

The Virginia Board for People with Disabilities (VBPD) through its participation in statewide workgroups has expressed concern that the current DMHMRSAS regulations (*Rules and Regulations for the Licensing of Providers of Mental Health, Mental Retardation and Substance Abuse Services*, authorized under *Code of Virginia*, § 37.2-404) combine into one set of regulations, standards, and requirements for licensed programs serving persons with mental health, intellectual disabilities, and substance abuse support needs. Virginia's licensure regulations are tied to a medical model approach to services. This approach is counterproductive to systems transformation and incorporating PCP in a *real* way into the daily policies and practices of residential providers, licensing specialists, and stakeholders. This dynamic can create a focus on quality of care versus quality of life inhibiting the latter for persons with intellectual and developmental disabilities. In querying other states, VBPD found that many were surprised that Virginia's regulations were combined for populations that have such varying needs with respect to services and oversight. Regulations that promote health and safety and quality of life do not have to be mutually exclusive but do need to acknowledge the challenges while fully integrating the values inherent in a person-centered system in policy.

Quality of life indicators must of course be accompanied by adequate monitoring and oversight. The number of licensure staff members has not kept pace with the vast, increasing number of community providers that require monitoring. In the past two years, separate reports have indicated that the current system of state licensure and compliance enforcement has significant inadequacies and needs improvement. In 2006, the DMHMRSAS Office of the Inspector General released a study, *Review of Community Residential Services for Adults with Mental Retardation, Report #126-05*; and the Joint Legislative and Audit Review Commission (JLARC) released its evaluation study of children's residential services funded by the Comprehensive Services Act (CSA). Although these studies differed in the scope of services examined, both pointed out that licensure office staffing in state agencies was inadequate to provide sufficient oversight of the quality of community services; and they recommended identification of and funding for appropriate levels of staff. Both, to varying degrees, recommended that licensure standards be strengthened to include assessment of consumer quality of life and person-centered planning and to strengthen current standards, such as quality of care and staffing levels/qualifications, to better ensure health and safety.

The Governor's proposed budget for 2008 included an additional 4 licensure/investigation positions for DMHMRSAS.

## Board Recommendations for Community Living Supports

In putting forth the following recommendations, which certainly do not represent all changes and improvements required for the Commonwealth's disability service system, the Virginia Board for People with Disabilities (VBPD) would like to begin with the following quote from *The Status of Institutional Closure Efforts* (2005):

Clearly, cost, service quality, and lack of available successful community alternatives are not the reasons ... institutions remain open. Instead, institutions for persons with ID/DD remain open because some states lack the political will to close or downsize them. Most states provide community supports to most or all of their citizens with ID/DD. Most states have made policy decisions that acknowledge the substantially better quality of life and quality of care in community settings, and which support the right articulated in the New Freedom Initiative for individuals to be free of unnecessarily restrictive living arrangements. The hope is that the others will soon provide similar opportunities to their citizens with disabilities.

1. **Eliminate the Current Dual System of Services:** VBPD continues to recommend that the current institution-based service model be replaced with a defined core set of community-based supports and services that are available on an equitable basis statewide. The Commonwealth should alter its commitment of financial resources to focus on immediate development of new community-living opportunities as an alternative to institutionalization. Every dollar spent on a Training Center is money not available for community services. The identification of core services in communities statewide should be regarded as a minimum step and should not preclude the development of flexible, new services or the creative utilization of natural supports for which funding may be needed. To address the fear of losing state jobs as a result of state facility downsizing, VBPD recommends that the Commonwealth develop and support jobs in the community for workers who would be affected by downsizing. Virginia should use the model of other states that have provided for comparable wages for direct care professionals and paraprofessionals who support people with intellectual and/or developmental disabilities as they move from institutional to community-living arrangements.
2. **Develop an Inclusive Service System not Based on Disability Diagnosis:** VBPD recommends that the Commonwealth develop and fund a system of services that provides for equitable access to lifelong services, is not dependent solely on Home and Community Based Waivers for funding support, and supports persons with disabilities regardless of specific diagnosis or eligibility for Home and Community Based Waivers. In particular, the statutory focus of the Department of Mental Health, Mental Retardation and Substance Abuse (DMHMRSAS) system on one developmental disability—intellectual disability/mental retardation—has meant that policy, planning, services, and supports for other populations, including but not limited to autism and brain injury, have lagged. VBPD was pleased to

participate in the work undertaken by the Joint Commission on Health Care to recommend a “home for Autism” but believes that these efforts should be expanded beyond Autism and that planning and funding services by disability category will result in continued fragmentation of the service system and competition by disability “category” for funding and other resources.

3. **Revise Current Home and Community Based (HCB) Waivers:** VBPD recommends that the Commonwealth consider consolidating Home and Community Based Waivers rather than developing individual waivers for specific populations that continue to promote the disability “silos” discussed above. All Home and Community Based Waivers should be driven by person-centered practices and provide a menu of services from which the individual can choose. In instances in which ongoing training is needed for an individual to access services (such as training in the use of assistive technology), such training should be covered under the HCB Waiver. Consolidation should only be considered if meaningful choice is provided for all Medicaid State Plan or waiver services that would be provided under a consolidated waiver or waivers. VBPD also recommends that existing Home and Community Based Waivers be redesigned to include all supports and services that can be provided through ICF-MR funding, and in particular, services for persons with complex medical needs. This is feasible; it has been done in other states; and it would eliminate the contention and misperception that certain services can only be obtained in an institutional setting.
4. **Improve Access to Home and Community Based (HCB) Waivers:** VBPD supports the recommendations of DMHMRSAS, the Arc of Virginia, and others to make a significant increase of funding to develop community services, eliminate the HCB Waiver Waiting List and in the interim, and bring the waiting period to reasonable timeframes and predictable levels. VBPD also recommends that access to the MR Waiver be provided for persons in non-state-operated intermediate care facilities for persons with mental retardation (ICFs-MR) and in nursing homes in the same manner as they are available to persons residing in Training Centers. DD Waiver slots are already available to this population. VBPD recognizes the position of advocacy groups that fear that placing persons who reside in institutions on the MR Waiver waiting list will simply lengthen that list. VBPD believes, however, that the true need for waiver slots should be documented and that persons with intellectual disabilities residing in all institutions should have the opportunity to move out of those settings if they so choose. At present, they have little hope of moving to the community because their health, welfare, and safety are presumably being met in the institutional setting. The Money Follows the Person initiative is a positive step in this direction, and it will be important to study the outcomes of this demonstration initiative.
5. **Study Administration of Home and Community Based (HCB) Waiver Waiting Lists:** In 2006, VBPD recommended statewide administration of the Mental Retardation (MR) Waiver Waiting List (see Areas of Concern). In response to opposition from and concern expressed by the intellectual disabilities advocacy community, including the Virginia Association of Community Services Boards and the Arc of Virginia, VBPD recommends that the Joint Legislative and Audit Committee (JLARC) consider conducting a study of waiting list administration under the MR and Developmental Disabilities (DD) Waivers. As an

independent legislative body with extensive and well-regarded research credentials, JLARC can conduct an objective independent examination and provide recommendations regarding the strengths and weaknesses of local waiting list administration, statewide waiting list administration, waiting list criteria for both waivers, and any other matters affecting planning and provisions of services to persons on HCB Waiver Waiting Lists.

6. **Increase Provider Rates and Establish Improved Rate Structure:** VBPD recommends that Virginia follow the lead of other states that have implemented initiatives for significant improvement of wages and provide or facilitate health-care coverage and other benefits to direct care workers serving persons with disabilities. VBPD also recommends that the Commonwealth expand incentives for providers who serve individuals in community-living settings, including group homes, but recommend enhanced incentives for the development of supervised apartments, supported living, and other noncongregate living arrangements.

VBPD commends the elimination of the rate disparity between supported employment services funded by the Department of Rehabilitative Services versus those funded under the MR or DD Waivers and recommends the elimination of all such rate disparities. The Board further recommends annual cost-of-living adjustments, regional differentials where needed, and establishment of an intensity-based rate structure that will give incentives to community-based providers to serve persons with more complex and challenging needs.

7. **Increase Personal Maintenance Allowance:** VBPD recommends that Virginia increase the personal maintenance allowance (PMA) for people who receive Home and Community Based Waiver services so that citizens can keep up to 300 percent of Supplemental Security Income (SSI), currently \$1,911 based on the 2008 \$637 monthly SSI maximum payment.
8. **Ensure Provider Choice in All Home and Community Based (HCB) Waiver and Medicaid State Plan Services:** VBPD recommends that the Commonwealth provide individuals with disabilities with a choice in all services and providers of services funded through HCB or Virginia's Medicaid State Plan. To facilitate choice and clear understanding of options by persons with disabilities, DMAS should develop standardized statewide forms for service plans developed under the various HCB Waivers.
9. **Address Gaps in Services to Persons with Brain Injury:** VBPD defers to the recommendations in the September 2007 Joint Legislative and Audit Review Committee (JLARC) report on Access to Brain Injury Services in the Commonwealth. We also agree with the Department of Rehabilitative Services that continued development of a network of "core services" for persons with brain injury (i.e., Regional Brain Injury Resource Coordinators, Specialized Brain Injury Case Managers, and Vocational Clubhouse/Day Programs) is critical to addressing needs in unserved and underserved areas of the Commonwealth. The "core services" are designed to support individuals with brain injury in the community, to prevent placement in institutional settings, and to support the community reentry of people following institutional placement. VBPD recommends exploring the appropriate mechanisms to provide funding for residential neurobehavioral services for people at risk of institutional placement caused by challenging behaviors, since there are no

funds currently available for these critically needed specialized services. A Brain Injury Waiver has been under consideration for a number of years but has not been approved for funding.

10. **Maximize Availability of and Resources for Centers for Independent Living:** Consistent with the 2008–2010 State Plan for Independent Living, VBPD recommends expansion of Centers for Independent Living (CILs) to currently unserved geographic areas of the state. VBPD also recommends that current funding levels of Virginia’s CILs be reviewed in light of the recommended national average for CIL funding. VBPD recognizes that the current data collection system is federally mandated and standardized; however, CILs may want to look at supplementing these required data to focus more on outcome versus output data, and VBPD recommends conducting additional analyses of these data for better support of funding requests. This should include an analysis of the number of individuals unable to be served because of a lack of resources and the specific needs that could not be met. Identification of gaps in services within and among CILS could help focus resources on those CILs most in need.
11. **Ensure Quality of Life, Health, and Safety in DMHMRSAS-Licensed Community Living Settings:** To alleviate individual and family fears of transition to community-based settings, and particularly congregate settings, the Virginia Board for People with Disabilities (VBPD) recommends consideration of a number of steps to ensure quality of life, maximum self-determination, and safety. Some of these recommendations were also included in the *2006 Biennial Assessment*.
  - A. VBPD recommends that the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMSRAS) consider restructuring its licensure regulations affecting persons with intellectual disabilities and that it review current regulations in light of more-progressive regulations in other states, including but not limited to the Commonwealth of Massachusetts. As noted earlier, Virginia’s licensure regulations (*Rules and Regulations for the Licensing of Providers of Mental Health, Mental Retardation and Substance Abuse Services*) are tied to a medical model approach to services that may well be appropriate for the population of individuals with mental illness or substance abuse challenges but has significant weaknesses with respect to appropriately serving persons with intellectual and developmental disabilities. Massachusetts has developed licensure regulations specific to the population of individuals with intellectual disabilities that include a licensure and certification process. The licensure process gives the provider legal authorization to provide services or supports, and is based on the presence of essential safeguards in areas relating to health, safety, and rights. The certification process is one by which outcomes in people’s lives, in addition to health and safety, are reviewed. These include relationships, community connections, and individual control and growth accomplishments. These outcomes are equally as important, but can occur over time and are part of a provider’s ongoing service enhancement process. Massachusetts has been refining and improving its licensure and certification process since 1994 and it is a national model.

- B. In the interim, with the knowledge that regulatory restructuring would be a lengthy and complex process, VBPD recommends that licensure requirements be revised to ensure that oversight includes quality of life indicators. Requirements should mandate that congregate-living providers have a Quality Assurance (QA) plan specific to each congregate home site and that staff training on the QA plan is documented. DMHMRSAS licensure regulations should reflect a requirement that persons living in licensed congregate settings have person centered plans and supports that meet their unique needs and preferences, not just with respect to the individual's life in that residence, but with respect to his or her broader community-living goals and options such as employment and greater independence, if desired by the individual.
- C. VBPD continues to recommend that the Commonwealth consider establishing "tiered" licensure, and appropriate differential funding, for congregate residences in the community that specialize in serving specific populations, such as those with intellectual disabilities and co-occurring mental illness. Such providers would have direct care staff members who, by verifiable documentation, have the particular skills and knowledge needed to serve the individual best. Each tier or level of residential service could be based on the level of needs of the individuals served, the intensity of supports needed, and "best practices." This concept was also recommended in the strategic plan of the DMHMRSAS Intellectual Disabilities Special Populations Workgroup, which is comprised of a wide variety of stakeholders statewide.
- D. VBPD recommends that DMHMRSAS continue to work with individuals with disabilities, their families, and community providers to explore creative options for creating local network, Microboards, and "circles of supports" for vulnerable individuals. The creative support options involve a group of people, usually volunteers, who meet together on a regular basis to help somebody accomplish his or her personal goals in life, acting as a community around the individual who needs assistance. Microboards (which are legally incorporated) and circles of support assist individuals to overcome obstacles and increase the options that are open to them and to ensure on an ongoing basis that the work is consistent with the individuals' personal goals and choices. A recent grant funded by VBPD that focused on the development of Microboards for persons residing in training centers and in the community resulted in the identification of obstacles in both policies and practice that serve as barriers to increased utilization of these creative support options.
12. **Improve Access to Quality Interpreter Services:** In consultation with the Virginia Department for the Deaf and Hard of Hearing, VBPD recommends a comprehensive study of sign language interpreters in Virginia, including but not limited to training needs (both currently available and needed to satisfy the demand), recruitment (both of qualified interpreters from other areas of the country and new interpreters), discovery of successful models in other states, and credentialing. The study should be conducted by a qualified researcher and include representatives from the Deaf Community, the Interpreting

Community, and Interpreter Trainers. The study should collect and compare data on interpreters in Virginia with those in other states and provide recommendations relating to technology, training, and incentives.

13. **Increase the Availability of Consumer-Directed (CD) Services and Implement Individualized Budgeting:** VBPD recommends that to the maximum extent possible, consumer-directed services and individualized budgeting be an option in all Home and Community Based (HCB) Waivers. Individualized budgeting paired with CD services promotes flexibility, control, and choice over support needs and services. It can also assist with filling some of the current service system provider capacity gaps. Of note is that individualized budgeting is a goal of the Systems Transformation Grant (STG) currently underway with the Department of Medical Assistance Services as the lead agency. At present STG staff members are conducting a review of policies/procedures in states that currently include individualized budgets as an option in order to identify changes and enhancements needed in Virginia's policies and procedures to support the use of individual budgets. Following this review the STG team will complete a plan to address inconsistencies and needed changes between all existing state policies and procedures, including dates by which all needed changes will be made and the agency responsible for making them, as well as other logistical and training needs. A report will be developed on how to calculate individual budgets in Virginia. All of this must be approved by the federal Center for Medicare and Medicaid Services (CMS).
14. **Support Alternatives to Guardianship:** VBPD recommends that the Commonwealth review its current substitute decision-making alternatives and explore processes by which the state can build capacity to support decision-making through alternative means. A number of states have alternative decision-making models that are more responsive to individuals with disabilities and that allow for a higher degree of self-determination for persons with developmental disabilities for whom decision-making support may be needed. The barriers in law, regulation, and policy to increased self-determination for persons with developmental disabilities should be addressed. User-friendly information on options and alternatives should be readily available to families and professionals.

## V. Institutional Care and Supports

### Areas of Concern for Institutional Supports

The chapter detail provides information on the breadth and depth of services available to persons with disabilities in institutional settings. Cited throughout the chapter are important statistical data regarding program activities, persons served, and other relevant data. Section G focuses on the specific areas in which further improvements may be needed to move the system forward and ensure that the needs of students with disabilities throughout the Commonwealth are met. The Virginia Board for People with Disabilities (VBPD) identified the issues and concerns below through a variety of mechanisms, including: (1) review and analysis of the numerous source documents referenced within and listed at the end of this chapter, (2) public comment received via VBPD's six public forums held throughout the state in the spring of 2007, and (3) written comment and information provided and verified by state agencies in their reviews.

The concerns below are not all-inclusive, but represent those that VBPD has identified as important to systems improvement. The concerns are not listed in any order of priority.

- 1. Effect of Institutional Entitlement on Systems Transformation:** A continuing challenge for persons with significant disabilities in Virginia is that nursing home and ICF-MR facility services remain an entitlement, while community-based services are not an entitlement. Although nursing facilities are established as an entitlement by federal regulation, ICFs-MR services are an entitlement because Virginia has chosen ICF-MR as an "optional" service in its Medicaid State Plan. While progress is being made toward rebalancing the current system, the institutional entitlement continues to be a factor in maintaining a disproportional funding commitment to institutions while community services remain under- or inconsistently developed. Since state moneys are finite, the costs of running institutions (and in the case of Training Centers, also renovations to maintain current federal standards) ultimately take significant resources away from community services.
- 2. Concern over the Growth of Smaller Institutions:** The Board continues to be concerned about the number and utilization of smaller institutions, such as Intermediate Care Facilities for persons with mental retardation (ICFs-MR) and nursing facilities. As noted in the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) *Study of the Mental Retardation Service System*, comparatively low reimbursement rates and lack of funding for "general supervision" exert a negative impact on staffing and expansion of more individualized residences. The higher funding levels for ICFs-MR and nursing homes can be an unintended incentive to convert group homes or other types of congregate living residences into ICFs-MR. In addition, the elimination of the requirement for a Certificate of Public Need (COPN) for ICFs-MR having up to 12 beds facilitates development of new institutions, and may be responsible in part for the growth of larger ICFs-MR such as the recent 24-bed (2–twelve beds) ICF-MR in Virginia Beach. As noted in the chapter detail, since 2005, the Department of Health has recommended ICF-MR certification for conversion of eight group homes. This is a trend that raises concern.

Several participants in the 2007 public comments events stated that the Board has a bias against ICFs-MR and urged the Board to alter its position. The Board understands that ICFs-MR may be the only option available to individuals who need services in a state with limited resources. The Board believes, however, that the development of community infrastructure and services should focus on noninstitutional options, and is pleased that the DMHRSAS 2007 *Study of the Mental Retardation Service System* supports this focus. With an appropriate design and funding of Home and Community Based (HCB) Waivers, any service provided by a licensed institution can be provided in the community with equal effectiveness to the consumer and at less long-term cost to the Commonwealth.

- 3. Lack of a Comprehensive, Integrated Inter-Agency “Blueprint” for Services to Persons with Intellectual Disabilities (ID):** Similar to other individuals with disabilities, persons with ID are served by a number of state agencies and funding streams, among which DMHRSAS has been central. Issues surrounding the maintenance of state Training Centers, for example, are complex and are highly interrelated with numerous other state policy decisions, especially covered Medicaid services and reimbursement rates, infrastructure development, community capacity-building, and workforce development. Initiatives such as those conducted by the Office for Community Integration and those led by the Department of Medical Assistance Services—including Money Follows the Person and System Transformation—are strengthening interagency partnerships in planning system change; policy disconnects, however, still exist. A long-range plan is needed for the future intellectual disabilities system that operationalizes the steps to be taken—specific Medicaid as well as infrastructure and service components to be developed, as well as regulatory changes—and measurable objectives with timeframes for completion. The DMHRSAS 2007 *Study of the MR Services System* is a positive step towards creation of a blueprint.
- 4. Inadequate Discharge Planning/Case Management for Persons Residing in State-Operated Training Centers:** Unlike admissions to state mental health facilities, state Training Center admissions have been considered to be long-term, even lifetime, in nature. This is evident from data relating to the average length of stay in Training Centers. The Training Centers are beginning to be used for short-term crisis stabilization, however, especially for those with intellectual disabilities and co-occurring mental illness or severely challenging behaviors. As stipulated in the *Code of Virginia*, in planning discharge for a person receiving services in a state facility, a clinical decision determines whether the individual is “ready for discharge.” For Training Center residents, most of whom were admitted decades ago, the determination of clinical readiness is not relevant. Instead, discharge as an option is directly related to whether adequate supports and services are available in the community, and whether the individuals or families (or authorized representatives, as appropriate) wish community placement and waiver services, and whether a waiver “slot” is available to them. The revised *Rules and Regulations to Assure the Rights of Individuals Receiving Services from Providers of Mental Health, Mental Retardation and Substance Abuse Services* (12 VAC 35-115-70) issued in the fall of 2007 now state that Training Center staff members must notify the appropriate Community Service Board (CSB) immediately of a resident’s request for discharge.

The CSBs are responsible for providing case management and discharge planning services to persons residing in Training Centers. As noted in the DMHMRSAS Inspector General's 2007 study, *Mental Retardation Case Management Services for Adults*, only five CSBs assigned active case management status to the residents. The 2007 DMHMRSAS MR Waiver Study reported that many family members of Training Center residents prefer that placement because of perceived permanence, safety, and oversight. As noted by the University of Minnesota Institute for Community Living, however, fear often is a key barrier to overcome in developing community-focused and person-centered services. Since admissions have historically been considered long-term, the reality of whether meaningful discharge activities occur that would truly facilitate future planning on a person-centered level (for example, exploring potential community-living opportunities) is unclear. Most important, in order for individuals, or their families or authorized representatives, to make the choice of community-based services, real choices in services need to be readily available and funded.

- 5. Inadequate Information Provided to Individuals with Disabilities and Their Families:** Many families continue to be unaware of the difference between a small intermediate care facility for persons with mental retardation (ICF-MR) and a group home funded through individuals receiving Home and Community Based (HCB) Waiver services. The Virginia Board for People with Disabilities (VBPD) and the Medicaid Waiver Technical Assistance Center located at the Endependence Center in Tidewater continue to receive reports of families who are already utilizing HCB Waivers agreeing to institutional placements or agreeing to allow their family member to remain in a group home that is converting to an ICF-MR without adequate information or understanding that, in doing so, their waiver slot will be forfeited. Often the institutional residents are referred to as group or "community" homes, creating further confusion for families. Subsequent options to change their desired living situation within Virginia are greatly reduced for these individuals when they give up their waiver slot.
- 6. Health, Welfare, and Safety Conditions at the Training Centers:** Both institutional and community service providers must ensure the health, welfare, and safety of its service recipients and residents in the case of residential providers. The aging and condition of state Training Centers continue to cause major concerns for the dignity, safety of, and active treatment services to residents. As noted in the 2007 DMHMRSAS *Study of the Mental Retardation Service System*, the building design and residential space at state Training Centers often is no longer adequate to meet the needs of residents, which have changed over the decades; and "significant physical plant improvements to ensure the continued health and safety of their residents" are needed. As noted in the chapter, Medicaid certification/recertification and related inspection surveys during 2006 and 2007 identified problems regarding safety and maintenance of buildings as well as quality of clinical care.

Also related to these inadequate buildings' issues, as part of its public comment on revision to the Human Rights regulations, the Board noted that the abuse and neglect oversight system can be problematic. In contrast to the Human Rights Advocates who are hired by and report directly to the Director of the Office on Human Rights, abuse and neglect

investigators are facility employees who report to the facility Director, and the Manager for Abuse and Neglect is hired by and reports to the Associate Commissioner for Facility Management.

- 7. Children Being Served in Nursing Facilities and Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR):** Though the numbers have declined since 2004, youths ages 20 and younger with disabilities are still being served in institutions. Families often do not receive the information they need to make real choices and are unaware of the potential option of a Home and Community Based (HCB) Waiver. Sufficient services and supports, especially medical and nursing care, must be made available to families so that they can care for their children at home if they choose to do so.

The Virginia Board for People with Disabilities (VBPD) remains concerned about the number of children with disabilities in ICFs-MR and nursing facilities, and the efforts of some advocates to loosen criteria for admission of children into Training Centers. Both public comment provided to VBPD as well as the experience of several of its own Board members indicate that families who choose institutional placements are often not aware of community-living options and supports such as HCB Waivers. As noted above in Issue 5, sometimes families already utilizing HCB Waivers agree to institutional placements without adequate information or understanding of the consequences. In Northern Virginia, three ICFs-MR actually use “group home” in their names, creating further confusion for families as to whether the residence is an HCB Waiver home or an ICF-MR. In 2007, VBPD awarded a grant to the Virginia Association of Centers for Independent Living (VACIL) to conduct outreach to families of children at risk of placement in an institution or children currently in institutions. The goal is to help interested families learn about and obtain community supports to preserve the family or to rejoin the family by helping to transition the child back into the community.

- 8. Erroneous Perceptions Regarding Care and Support of Individuals Who have Complex Medical Needs:** There continues to be misconceptions regarding how to serve people who have significant needs, including those perceived as “medically fragile.” Too often an assumption is made by health care and other professionals that these individuals can only be served in an institution. Research has shown that with the appropriate services and supports, persons with complex medical needs can, in fact, be served in their homes or in other community settings. As additional evidence of this, a 2006 Virginia Board for People with Disabilities grant to the Virginia Association of Centers for Independent Living (VACIL) resulted in 45 individuals transitioning out of nursing homes and into independent or family living, non-congregate settings.
- 9. Isolation of Residents at Training Centers:** According to the 2005 Office of the Inspector General (OIG) for the Department of Mental Health, Mental Retardation and Substance Abuse Services *Systemic Review of State Training Centers*, the degree to which Training Centers offer activities that promote community integration (i.e., leaving the campus for activities), is variable and limited, being most limited at the larger facilities. Over time, facilities built (often with family support) features that keep services self-contained on

campus, such as swimming pools, rather than partner with community resources (such as YMCA/YWCA) to promote more-normalized experiences with community members. As long as residents remain isolated within Training Centers, their segregation is counter to community integration and, most important, promotes misconceptions that these individuals cannot be served in the community, which thwarts systems transformation.

**10. Lack of Person-Centered Practices for Persons Residing in Institutions:** The

Commonwealth has been engaged in instituting person-centered practices (PCP) into the service system for close to twenty years and has invested significant resources in trying to do so; yet, person-centered practices still elude many who receive services, especially those in institutional settings. The values and service delivery approaches fundamentally embedded in a system that promotes person-centered thinking and principles 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 and regardless of the agency either funding or operating the service. A core understanding of these values and implementation of the associated principles and practices is especially important at nursing facilities, ICFs-MR, and other institutions to ensure maximum consumer choice in an environment that can otherwise inherently limit such choice.

## **Board Recommendations for Institutional Supports**

The Virginia Board for People with Disabilities puts forth the following recommendations relating to policy and practice that would encourage and promote true choice for residents of institutions.

- 1. Equalize the Entitlement Status of Institutions and Community Living:** The Virginia Board for People with Disabilities (VBPD) continues to recommend that the Medicaid State Plan be amended so that Home and Community Based Medicaid Waiver services be given the same entitlement status as currently exists in Virginia for ICF-MR (institutional) services.
- 2. Implement Person-Centered Practices (PCP) Systemwide:** VBPD recommends that training and education on person-centered practices, including values, planning, and support, be expanded throughout the service delivery system and included in university programs and continuing education for human services. To effect a systemic paradigm shift, aggressive state leadership is needed to set expectations, develop policies and protocols, revise regulations, and expand training. Person-centered principles and practices (PCP) need to be universally understood and integrated into the fabric of planning and service delivery for individuals with disabilities at every level regardless of the environment in which the services are being provided. There are three current initiatives that each have a specific goal to bring person-centered services and practices to the service system: the Money Follows the Person Demonstration Project, the Systems Transformation Grant, and the Person-Centered Planning Workgroup assembled by the Department of Mental Health, Mental Retardation and Substance Abuse Services in response to the Office of Inspector General's (OIG) recommendations from OIG Reports 126-05 and 127-05. In order to ensure that these

current initiatives actually bring PCP to the forefront of service delivery—with systemic versus splintered success—it is important to gain an understanding of why past attempts have failed. The strategies used and barriers confronted need to be identified, discussed, assessed, and fully understood with questions such as “Why didn’t this work before?” and “What do we need to do differently?” asked at each juncture of planning, implementation, and evaluation.

- 3. Provide Active Case Management Services to Persons Residing in Institutions:** VBPD recommends that the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) work with community services boards (CSBs) to ensure that discharge planning for individuals with intellectual disabilities/developmental disabilities who reside in training centers is an ongoing process that begins at admission. Quarterly reviews should be comprehensive and meaningful. VBPD recognizes that additional funding may be needed in order to provide active case management to all training center residents. The work of the five CSBs that already do this should be examined to ascertain how they are able to conduct these activities and the results thereof. Residents, family members, and authorized representatives should be provided with information on potential community living options on an ongoing, face-to-face basis by the appropriate entity. Long-term residents of institutions, including those who have authorized representatives, should be afforded the opportunity for community experiences that will enable them to explore their wishes and support options. Within confidentiality guidelines, families should be provided information about individuals who have successfully transitioned into the community following long-term institutionalization.
- 4. Implement a Moratorium on Conversion of Home and Community Based (HCB) Waiver Funded Group Homes to Intermediate Care Facilities for Persons with Mental Retardation (ICF-MR) Status:** The Commonwealth should provide funding support and incentives to encourage the immediate development of new community-living opportunities, including noncongregate living options, as an alternative to institutionalization. While VBPD is strongly opposed to ICFs-MR and supports individualized living options, it recognizes that the creation of new ICFs-MR has continued because of the underfunding of community alternatives. VBPD therefore also recommends that the state limits the size of any new ICF-MR to no more than four beds and provides sufficient funding to create alternatives so that ICFs-MR of any size need not be built.
- 5. Eliminate the Institutionalization of Children in Virginia (Younger than Age 21):** VBPD believes that families should never have to make the difficult decision to place their children in an institutional setting because they cannot obtain the services and supports they need within their homes and local communities. The Commonwealth should make a clear commitment to providing sufficient long-term funding to develop and maintain services that will allow children to grow up with a family. VBPD recommends that the appropriate executive branch or legislative agency conduct a study to examine the reasons for admissions of children and youths to training centers, nursing facilities, ICFs-MR (state and non-state), and long-stay hospitals to include contributing community service gaps, length of stay, impact of long-term institutionalization on family relationships, cost comparison to

community services, and identification of successful strategies in other states to support youths and families in the home.

VBPD recommends that Virginia follow the lead of the State of Georgia, which in 2005 developed a goal of “a Georgia where children are prevented from going into institutions/facilities or are brought safely home from institutions/facilities into homes and families.” As a result of this goal, the Georgia legislature passed a resolution that required nursing homes, state hospitals, private ICFs, and public and private hospitals serving children in long-term care submit an annual progress report to the Speaker of the House and develop a budget proposal for the 2008 fiscal year. It also established an oversight committee comprised of members of the three federal partners and other interested stakeholders, including legislators, to monitor the progress of the agencies. A summit was held to discuss ways for successfully moving the children to permanent homes and families. In 2006, the Georgia legislature approved funds so that all of the children in its state-administered institutions could go home. The state continues to work on this same goal for children in private facilities and nursing homes.

## VI. Health Care

### Areas of Concern for Health Services

Since the release of the 2006 *Biennial Assessment*, Virginia has made progress in improving health services for individuals with disabilities; however, difficulties in accessing services remain. During this time, the Governor's Health Reform Commission has carefully studied the state's overall health-care system. The Board commends its work and notes that many of the issues that it addressed have also been identified, with specific regard to the health and wellness needs of persons with disabilities, in public comments received by the Board and its partners.

Without duplicating the Commission's efforts or unnecessarily citing the details in its report, the Board strongly encourages consideration of its conclusions regarding Long-Term Care; Access to Care; the Health Care Workforce, which includes direct support workers; and Quality, Transparency, and Prevention. Critical issues covered in each of those areas directly affect the lives of persons with developmental and other disabilities. Other specific findings of the Commission are cited where appropriate under the concerns described below.

While its list is not all-inclusive, the Board believes that recognizing and addressing the following concerns are critical to systems change. These concerns have been identified through a variety of means, including careful review and analysis of the source documents listed at the end of this chapter. Health and wellness concerns were also raised by participants in its six Stakeholder Roundtables and six Public Comment Forums held across the state in the spring of 2007 and in written public comments submitted during that same period. In addition, the Board receives thoughtful, well-informed feedback from its fellow participants in the Virginia Department of Health's (VDH) Health Promotion for People with Disabilities (HPPD) Task Force on an ongoing basis. HPPD deserves special recognition for bringing together stakeholders from the public and private sectors at the state and local levels to raise awareness of health and wellness concerns for persons with disabilities and to identify and collaboratively seek solutions to persistent problems.

1. **Lack of Health Insurance:** Specifically addressed by the Health Reform Commission, concerns about this issue have not abated in any sense since the 2006 *Biennial Assessment*. Under our current health system, access to necessary care is directly dependent on the affordability of insurance. The Commission reports that 1.1 million Virginians, 15.5 percent of the total state population, are uninsured. Some individuals with disabilities are covered through their employment; nevertheless, large numbers of individuals with disabilities are unemployed, work part-time, or work full-time for employers that do not provide insurance or whose policies provide only limited coverage. Of these, some are covered by other private insurance programs, and more are covered by Virginia's public insurance programs such as Medicaid (FAMIS Plus) and FAMIS. This still leaves many others without coverage, including those whose family incomes, while modest, are sufficiently high to make them ineligible for the public insurance programs.

Higher rates of unemployment and generally lower family incomes contribute to significantly lower rates of insurance for persons with disabilities than for the general population. In addition, even those with basic health insurance may lack coverage for dental, optical, and other specialty services, and the growing complexity of insurance plans, particularly publicly funded plans, may effectively deny access to coverage. As noted by the Commission, rising demand for services under public health insurance programs, coupled with ever-rising costs for those services “may soon outpace resources.” As a result, cuts in eligibility, services covered, and provider reimbursement rates are a constant concern.

- 2. Lack of Dental Care:** While definitely of continuing concern, this issue has received much-needed attention since it was cited in the Board’s 2006 *Biennial Assessment*. Other advocacy groups have brought this issue to the forefront, and it was identified as a critical need in the Governor’s Health Reform Commission Report and in the DMHMRSAS Mental Retardation Study Report, also published in the fall of 2007. The Commission received 99 public comments related specifically to this issue.

Virginia’s Smiles for Children program addresses the dental needs of children whose families qualify for public health insurance programs, but in significantly large portions of the state, there are no dentists who participate or none who will accept additional patients. Many who do participate are insufficiently trained, equipped, or willing to accommodate the special needs of patients with disabilities. Among the reasons for not participating in Smiles for Children or for serving patients with disabilities, they cite a perceived high cost for accommodations, low public insurance reimbursement rates, and associated paperwork requirements.

Participants in the October 2007 “Strong Roots for Healthy Smiles” statewide dental summit reported that obtaining dental services for children with significant health needs or behavioral issues is difficult even where dentists who participate in Smiles for Children and other insurance programs are available. When general anesthesia is required, these children must be served in hospital settings. This incurs additional costs of time and resources for dental practices, often including the transport of special equipment not available in the hospital. Dentists must also have “hospital privileges” to practice in those facilities. Reimbursements, even at the higher rates permitted under certain circumstances, are structured for standard services in a dental office and are wholly inadequate to cover the extra costs. As a result, many dentists simply chose not to provide services in hospital settings.

Dental coverage for adults under Medicaid continues to be limited to medically necessary oral surgery, much of which could be prevented through less-costly regular dental checkups. Individuals “aging out” of Smiles for Children coverage experience a sudden and dramatic decrease in covered services, often with a lifetime impact on their general health.

- 3. Shortage of Health Care Providers:** Workforce shortages, including physicians, dentists, nurses, medical technicians, direct care workers, and other allied practitioners, was identified by the Health Commission Report as a significant barrier to providing Virginians with adequate health care. This shortage often results in a complete lack of providers available

and willing to treat persons with disabilities, especially when specialized training or equipment is needed and with growing numbers of practitioners declining to participate in public health insurance programs. The situation is particularly critical in rural areas and for specialties such as gynecology, obstetrics, pediatrics, and mental health where practitioners' costs are exacerbated by high malpractice insurance rates. Despite the growing demand for their services, inadequate numbers of physicians, especially specialists, are being trained to treat persons with intellectual and developmental disabilities, and as noted in the 2006 *Biennial Assessment*, none of Virginia's medical schools currently have a required curriculum component targeting this need.

Public clinics provide limited geographic and eligibility coverage, but frequently lack adequate accessibility for persons with disabilities, and are often inconvenient because of their limited operating schedules and long waiting times for service. Even when public clinics have capabilities to deliver specialty care, there is a perception that the quality of their care is inferior to that of private practitioners. This bias extends to both public and private institutionally based health care as well; although in some cases, quality of health care is cited as a positive attribute of the DMHMRSAS Training Centers. Pilot projects involving telemedicine are being explored partially to alleviate these problems in rural and remote areas where they are the worst, and recent news reports indicate that there have been some significant accomplishments in this area. The success of these efforts, however, is still restrained by attitudinal barriers on the part of both patients and practitioners and by lower reimbursement rates for teleservice than for in-office visits. Collectively, the lack of access to specialty providers, especially for individuals with disabilities, contributes greatly to delayed assessments, missed diagnoses, poorer health, and greater overall health-care costs.

4. **Complex Information and Lack of Outreach to Persons with Disabilities:** With increasing numbers of individuals living in communities, accessible and welcoming health and wellness opportunities are a growing requirement for effective community inclusion. Providers of public and private community health and wellness services are becoming increasingly aware of persons with disabilities as potential target populations, but, for the most part, opportunities for them to participate in health and wellness activities remain limited in number and segregated. Individuals with sensory or cognitive disabilities may also experience difficulties in gaining access to complex health and wellness information and in maintaining and providing necessary personal health records. Community service providers, information resources, and recreational facilities frequently lack training and experience in communications accommodations and access to interpretation services for both hearing-impaired and non-English-speaking populations.
5. **Lack of Physical and Operational Accessibility and Reasonable Accommodations in Health Care Settings:** Additional physical barriers to participation in health and wellness activities by people with disabilities exist because practitioners lack awareness and training in how to make appropriate accommodations or have unfounded concerns about costs and liability in providing those accommodations. Awareness and availability of assistive and adaptive technology, including accessible examination and treatment equipment, is also inadequate. Despite the provisions of the Americans and Virginians with Disabilities Acts,

facilities continue to be inaccessibly constructed and operated or are difficult to reach by public transportation. Accessibility is all too often misunderstood to mean only wheelchair accessibility. These persistent physical and attitudinal barriers to access to health and wellness opportunities are especially prevalent in rural agricultural regions and in rapidly expanding urban areas.

6. **Persistent Attitudinal and Cultural Barriers:** In some Virginia communities, there is still a strong stigma attached to acknowledgement of disabilities and chronic health conditions. Especially, in rural, remote, or other close-knit communities where “everyone knows everyone else,” there are concerns that public awareness of disabilities or illness may make an individual or family more susceptible to crime, abuse, or discrimination. Among certain ethnic and religious groups, the presence of these conditions is also seen as divine punishment and a source of shame. Despite anti-discrimination laws and substantial evidence to the contrary, employers may expect excessive time off the job and higher insurance costs and block hiring or promotion of both individuals with disabilities and their family members who care for them. Fearing public disclosure of their disabilities or illnesses, persons may be reluctant to seek services or travel out of their home area for assessments or services, delaying diagnoses and limiting care options. Cultural and ethnic beliefs about disabilities and public assistance lead some individuals to resist divesting real property such as land, businesses, vehicles, and equipment considered to belong to a family rather than a single person in order to be eligible for public insurance coverage or other publicly funded assistance.
7. **Need to Improve Coordination and Continuity of Care:** Individuals with disabilities of all kinds frequently receive medical and related services from a greater number of individual providers as a direct result of their disabilities or indirectly because of co-occurring health conditions. Coordinating these providers and maintaining related health and insurance records is complicated, which creates opportunities for omissions and errors. For lower-income families, where disabilities are proportionately more common, further complications arise from gaps in service and dependence on public clinics and providers willing to accept public insurance reimbursements.

For individuals with co-occurring mental illness and intellectual disabilities, especially those with no immediate family members readily at hand, the necessity for greater sharing of information and expertise among health and disability services providers is critical, particularly with regard to the understanding and administration of medications and the provision of appropriate cognitive and behavioral supports. Case managers, disability services coordinators, and other members of an individual with disabilities’ advocacy and support network may not be available during hospitalizations or in other health-care settings. Temporary guardians assigned in those settings may not understand or be fully aware of individuals’ treatment and support histories and disability-related needs and concerns. The lack of interpreters and other communications accommodations previously mentioned imposes additional difficulties for those with sensory disabilities, even those who can otherwise advocate and provide information on their own behalf.

Hospitalization itself may pose additional difficulties for individuals residing in community settings. Small community residences dependent financially on reimbursement for services bundled with housing may not be able to hold a resident's space until his or her return following extended hospitalization for medical treatment. When hospitalization is no longer required, hospitals and physicians are often reluctant to discharge individuals with disabilities back into community settings, preferring nursing homes or rehabilitation facilities instead, because of concerns about medical liability or a lack of understanding of available community supports that make such institutionalization unnecessary. Subsequent extended stays in such institutions can result in loss of eligibility for home- and community-based Medicaid waivers and ultimately prevent return to community residence.

8. **Need to Ensure That Integration of Acute and Long-Term Care Services Meet the Needs of Individuals with Disabilities:** In response to both federal challenges and its own fiscal and political pressures, Virginia like many other states is involved in ongoing reform of its public health insurance programs. Pursuant to Budget Item 302ZZ of the 2006 Virginia Acts of Assembly, the Department of Medical Assistance Services (DMAS) is moving from separate, "fee for service" systems for acute and long-term care services to a unified coordinated care system that combines Medicare and Medicaid resources and relies more on managed care funded on a capitated basis. Details of the state's plans can be found in DMAS's 2006 "Blueprint for the Integration of Acute and Long-Term Care Services." Elements implemented prior to the release of this report, particularly those relevant to the state's Medicaid Waiver programs, have been covered in the Community Living Supports chapter.
9. **Challenges Resulting from Current Nurse Delegation Requirements:** Under current Virginia regulations (CFR 18 VAC 90-20-240-460), individuals who are not licensed as nurses but who are properly trained, monitored, and evaluated may perform certain procedures or tasks that would ordinarily be performed by a nurse. Currently, certain unpaid individuals, such as family members, can perform these skilled services without meeting these "nurse delegation" requirements. Other individuals, including paid personal care assistants for individuals with disabilities, may only provide these services under a plan for delegation that includes an assessment and identification of the nursing-care needs and supervision, training, and monitoring by a nurse.

With increased availability of consumer-directed services, more individuals with disabilities wish to choose who will provide these skilled services for them. Nurse delegation enables that choice; however, Medicaid State Plan and Home and Community Based Waiver procedures are unclear as to how nurse delegation must be implemented for covered services and how health providers of services via nurse delegation, in both individual and group settings where nurses are not on staff, can be reimbursed for those services. Issues of liability in the event of an error by an unlicensed individual providing a nurse-delegated service are also unclear. As a result, home health-care providers and nurses are reluctant to participate in nurse delegation of services.

## Board Recommendations for Health Services

The concerns identified above are all important and deserving of attention, but in this report, the Virginia Board for People with Disabilities (VBPD) restricts its recommendations to areas where the need is most acute and there is the greatest potential for long-term improvements in the health and wellness of individuals with disabilities. Actions leading from these recommendations will ultimately result in an overall healthcare service system, public and private, which is more inclusive, more effective at preventing secondary problems, and more efficient in the use of public resources.

- 1. Expand Availability of Dental Coverage for Individuals with Disabilities:** VBPD recommends that Virginia take immediate steps to broaden publicly funded health insurance to include dental coverage for otherwise-eligible adults with disabilities. Steps must also be taken to ensure that dental services for both children and adults with disabilities are available in all Virginia localities currently lacking them and to increase the pool of available practitioners statewide. Outreach, incentives, and improved professional training must address existing physical, operational, and attitudinal barriers. Financial incentives must include a reduction in the gap between reimbursement rates for services to individuals with disabilities covered by publicly funded insurance and those enrolled in private plans. Publicly funded insurance reimbursement rates must also be restructured to give adequate compensation to dentists for providing services that must be performed in hospital settings for individuals with medical or behavioral concerns necessitating such care. Incentives and training, accompanied by ongoing technical assistance that includes information on available assistive technologies, must be provided for both new and existing practitioners that will enable and encourage them to make their services more accessible and welcoming to persons with disabilities.
- 2. Improve Professional Training for All Health Professionals:** In addition to the targeted training for dental practitioners described above, VBPD recommends that curriculum for physicians, nurses, and all other healthcare providers, at the earliest stages of professional training and to meet continuing education requirements, be strengthened to improve the availability and quality of community care for persons with disabilities. This curriculum should address the needs of individuals with intellectual and other developmental disabilities, in particular, and foster greater understanding of the basic human and civil rights requiring outreach to and accommodations for all individuals. It should provide cross-training on mental and physical health needs and practices specifically related to disabilities, information on assistive technology, and the most up-to-date information on early diagnosis and intervention. It should also address person-centered practices, self-determination, and other “dignity of risk” issues and promote a broad understanding of the abilities and potentials of persons with disabilities. Successful models and resources for improved practitioner training, including those produced by VBPD’s sibling developmental disability network agencies in other states, exist and are available for use in Virginia contingent on the will and resources to implement them.

VBPD further believes that training and practical experience in the “medical home” concept described earlier in this chapter should become a fundamental part of initial and continuing education for health professionals. Expansion of existing pediatric medical home programs and integration of medical home concepts throughout acute and long-term healthcare for both children and adults is essential to ensuring lifetime continuity of care and person-centered planning and decision-making across service disciplines.

- 3. Provide Incentives to Promote Community-Based Care:** Implementation of the recommendations above, in and of themselves, will still be insufficient to promote accessible, inclusive, and welcoming community-based health and wellness services. Additional financial, knowledge, and attitudinal barriers must be addressed to ensure that persons with the full range of disabilities have access to services without traveling long distances or reside in an institution.

VBPD recommends that existing incentives be expanded and new ones created to encourage both newly licensed and established professionals to locate inclusive practices in unserved and underserved areas of the state, such as remote rural areas and economically depressed urban areas, and to reach out to individuals with disabilities as clients. As already stated specifically for dental care, VBPD further recommends that reimbursement rates for publicly funded health insurance programs, such as Medicaid, be restructured and raised wherever necessary to establish parity with payments by private insurance plans. Similarly, situations where rate differentials may impede expansion of telemedicine should be identified and rectified, and attitudinal barriers that may discourage both providers’ and patients’ use of telemedicine should be addressed. Reimbursements must also be adequate to cover additional equipment, educational, or operational costs incurred in providing service to individuals with disabilities and participation in publicly funded insurance programs.

- 4. Identify and Promote Best Practices for Inclusive Health and Wellness Services:** The Virginia Department of Health’s (VDH) Health Promotion for People with Disabilities (HPPD) State Plan sets goals for determining the health and wellness needs of persons with disabilities and engaging new and existing providers to increase the availability and accessibility of services and promote their use. VDH has already initiated limited steps to improve its data collection and reporting, expand the outreach of its programs, and provide appropriate accommodations to make its programs more accessible to persons with disabilities. The HPPD Task Force, with VBPD’s and its other partners’ assistance and the limited resources available, has also begun identifying and publicizing examples of accessible, inclusive, and welcoming facilities and programs across the state, as well as programs in other states that can be emulated in Virginia. Unfortunately, while a number of accessible and welcoming programs exist, the number of inclusive programs is much smaller and significant knowledge and attitudinal barriers to their expansion exist.

VBPD recommends that these efforts be continued and expanded so that VDH and its state and local affiliates become role models for other providers in the areas of outreach, communications accommodations, and service accessibility. Resources should also be identified to support the production and dissemination of the best practices guide proposed in

the HPPD state plan using VDH's own practices and the others identified by HPPD as a foundation.

5. **Preserve Consumer Choice and Self-Direction of Health Services:** In Virginia and nationwide, the need to manage healthcare costs is leading to greater integration of acute and long-term care and the expansion of managed care. VBPD recognizes that, while these trends may potentially help to restrain rising costs, they may also inappropriately increase focus on the "medical model" for administration and funding of disability services. They may also have a negative impact on consumer choice and self-direction of services, disrupt or limit service delivery, and damage essential relationship built up between consumers and providers over many years. In the case of specialty care, they may restrict access to care that is recommended but may be more costly, reduce the number of available service providers, and unnecessarily fragment case management for health and long-term care.

To ensure that these negative outcomes do not occur, VBPD recommends close, ongoing monitoring of public and private efforts in these areas with full involvement in decision-making by persons with disabilities and their families. VBPD further recommends that the Department of Medical Assistance Services (DMAS) receives copies of all appeals of denial of service by managed-care providers and reviews them on an ongoing basis for prompt identification and resolution of systemic issues.

6. **Maintain SCHIP Coverage:** Virginia must affirm and sustain its commitment to providing services currently covered under the national State Children's Health Insurance Program (SCHIP). The Board recommends continued public and private vigilance and advocacy at the state and federal levels to ensure that children's healthcare remains available and affordable for Virginia's families.

## VII. Community Housing

### Areas of Concern for Community Housing

The chapter detail provides information on the breadth and depth of housing services, supports, and resources in Virginia. Cited throughout the chapter are important statistical data regarding program activities and cost-of-living and income barriers. The chapter detail also provides information on areas in which the system and services have improved and describes improvement activities and outcomes. Section G focuses on the specific areas in which further improvements may be needed to move the system forward and increase affordable and accessible housing capacity and choices. The Virginia Board for People with Disabilities (VBPD) identified the issues and concerns below through a variety of mechanisms, including: (1) review and analysis of the numerous source documents referenced within and listed at the end of this chapter, (2) public comment received via VBPD's six public forums held throughout the state in the spring of 2007, and (3) written comment and information provided and verified by state agencies in their reviews. The issues below are not all-inclusive, but represent those that VBPD has identified as important to systems improvement.

- 1. Need to Separate Housing and Support Services:** When housing and support services are tied together, individuals are vulnerable to funding changes and other pressures affecting the agency providing support. For example, those who provide both housing and services may choose to drop certain services. If the service they provide is required for the individual to reside successfully in that living environment, the individual can be evicted from the place of residence with no resource or appeal available to the person. In addition, with housing and services combined, persons with disabilities are not as free to change the providers from whom they receive services if they are dissatisfied with those services. In 2000, the President's Committee for People with Intellectual Disabilities stated: "People should have stable homes while fully exercising their right to choose the agencies who enter their homes to provide supports. Federal and local policy should affirm the separation of all programs specifically funding services or housing."
- 2. Lack of Coordinated Housing Planning:** The need for coordinated planning has been acknowledged by both the disability and housing communities. While there has been some progress, and strategies have been developed to address the need for greater understanding and education, the lack of coordination, consistent and effective influence, and integration of system change strategies that will have a positive impact on housing opportunities and options for people with disabilities in state planning processes and policies remain significant. Advocates and the disability community do not have a clear understanding of how the four housing planning activities by which disability advocates can influence the use of federal housing resources (the Consolidated Plan, the Public Housing Agency Plan, the Continuum of Care, and the Qualified Allocation Plan) operate on the local and state level. They are not sure what agencies prepare these strategic housing documents, how often they are prepared, and how to be a part of the planning process and develop positive relationships.

3. **Lack of Housing Options:** The lack of community resources for housing and other housing issues are a statewide concern and are well-documented by both the Virginia Housing Development Authority (VHDA) and the Department of Housing and Community Development (DHCD). These concerns illustrate a significant lack of housing options for people with disabilities (see Chapter detail). This lack of options exists for both properties that provide service coordination and supports for residents and properties that are heavily subsidized for low-income individuals with disabilities. To date, efforts to establish a Housing Trust Fund in Virginia have been unsuccessful. Increased efforts are needed to obtain a commitment of resources to support integrated housing options and choices. This is particularly important as we concurrently explore our long-term care system and needed changes to rebalance Virginia's allocation of resources from institutional settings to community settings.
4. **Inadequate Compliance with Fair Housing Practices:** Public comments indicate widespread landlord bias against low-income persons with disabilities and a reluctance to rent to persons whose primary source of income is Supplemental Security Income. Data from HUD's Office of Fair Housing and Equal Opportunity reinforce this concern. According HUD's 2006 Annual Report on Fair Housing: "In FY 2006, for the second consecutive year, disability was the most common basis for housing discrimination complaints filed with FHAP agencies. There were 2,851 such complaints filed, which accounted for 38 percent of the total complaints filed."
5. **Growing Demand Combined with Lack of Affordability:** The demand for affordable housing among people with disabilities will continue to rise rapidly because of the increase in life expectancy among people with disabilities and the advanced age of many family caregivers. As a Money Follows the Person (MFP) Demonstration Project recipient, Virginia has committed to support and lead rebalancing initiatives moving from an institutionally biased system to one that supports community inclusion, which further increases demand. Meeting this need will be difficult because of the very low incomes of many people with disabilities. Any substantial increases in their income will likely occur gradually, over time. Meanwhile, a large share of people with severe disabilities will continue to require deep subsidy assistance in order to find access to suitably located housing that is adequate to meet their needs. Exacerbating this situation is the trend of rising housing and rental costs statewide coupled with general increases in cost of living that further widen the gap between personal resources and need.
6. **Need for Transportation to Be Aligned with Housing:** The full inclusion of people with disabilities in their communities can only be accomplished by improving transportation and housing opportunities as a part of an interdependent system with unique needs and overlapping interests. Planning for improving the infrastructure and choice of accessible, affordable, and safe housing and transportation options in Virginia has been identified as a need by both transportation and housing entities. A lack of coordinated planning as well as inefficiencies in data collection and analysis on the housing and transportation needs of persons with disabilities on the local level creates a significantly impact on the assurance of consideration of these needs in planning processes. This coupled with an increased

need/demand for community-based accessible and affordable housing and transportation creates a barrier to community inclusion and citizen participation.

7. **Continued Community Resistance:** There continues to be an overall lack of accessible and affordable housing that is integrated into local communities. Compounding the issue is resistance in many localities to the development of housing options for people with disabilities, in large part caused by misconceptions, attitudes, and stereotyping. As recently as 2007, a neighborhood in Central Virginia expressed significant opposition to a group home located in their neighborhood. Issues of NIMBYism (Not In My Back Yard), in spite of Fair Housing protections, remain.
8. **Lack of Awareness of Universal Design and Visitability:** While progress has been made, there remains a broad lack of awareness across the housing spectrum (e.g., homeowners, builders, landlords, local and state officials, and operators of congregate living facilities) about the importance and benefits of universal design and visitability. Notable progress includes a coalition that developed in 2007 to bring EasyLiving Home (ELH), a voluntary certification program for new construction that meets key features of accessibility/visitability, to Virginia. In order for a home to be certified as an ELH, the home must contain the following features: (1) one zero-step entrance; (2) all main floor interior doors—including bathrooms—having 32 inches of clear passage space; and (3) at least one maneuverable half bath (preferably a full bath), bedroom, and entertaining area on the main floor. These features enable a person with a disability to *get in and out of the house and be able to use the bathroom*—the essentials for visiting, and for remaining at home with a temporary or long-term disability. Further promoting the importance of universal design and visitability, the 2007 General Assembly renamed the Home Modifications Tax Credit to the Livable Homes Tax Credit and expanded its use to new construction that meets the three key features of visitability. While these steps are positive, increased awareness and outreach education efforts across the housing spectrum are still needed.
9. **Philosophical Differences Regarding Community Housing versus Institutional Living:** Philosophical differences, such as those that surround institutional living versus community integration and group home living versus supported living and independent living, are still unresolved and present a barrier to progress. A vigorous debate continues among individuals with disabilities, family members, advocates, service providers, and officials on the strategies that would increase housing options. As we continue to promote culture-shifting from a medical model of services and supports toward that of inclusion and self-determination, it will become increasingly important to engage in discussion on these differences of philosophy, opinion, and expectation. Strategies need to be designed to implement change in a long-term and well-managed process.

## **Board Recommendations for Community Housing**

There are many individuals with disabilities who, if given the opportunity, would choose to live independently in their own residence, with or without supports. For this option to become a reality, people with disabilities need to be provided viable choices for accessible and affordable housing options. The availability of adequate housing is also a significant issue with respect to

the Commonwealth's ability to comply with the Supreme Court decision on *Olmstead v. L.C.* The Virginia Board for People with Disabilities (VBPD) offers the following recommendations to improve community housing available to Virginians with disabilities.

1. **Increase Knowledge of and Planning Based on Alternative Housing Models:** To create more housing that is affordable for people with disabilities, housing officials must be better educated about both the residential preferences of this population and the financing of subsidized housing that facilitates community integration. The types of housing preferred by some people with disabilities are independent apartments and homes or alternative housing that is integrated into the community rather than housing targeted either to persons with disabilities or more restrictively to persons with a specific type of disability.

The most creative and successful strategies require service agencies to think “outside of the box”—using all available housing resources and not just those targeted to the broad “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 for very-low-income homeless people with disabilities.

Housing models are, and will continue to be, needed that separate housing and services, allowing for choice in where and with whom a person lives. Separation of housing from services in community-based settings has been both a successful formal policy and standard practice in a number of states, such as Wisconsin, Michigan, Rhode Island, and Illinois. Individualized budgeting is one mechanism being used to promote such models, and it results in greater flexibility and independence in selecting housing and a service provider. VBPD recommends that the accomplishments and strategies used in other states be reviewed, discussed, and used to develop a framework for action in Virginia.

All entities and individuals with a vested interest in increasing housing opportunities and choices—state, regional, and local agencies, nonprofit and private organizations, advocates, and individuals with disabilities and their families—need to develop or strengthen collaboration and coordination of efforts. VBPD recommends development of training and other educational opportunities that will equalize knowledge, dispel myths and misinformation, promote common ground, and create a common vision.

2. **Provide and Prioritize Rental Assistance to Persons with Disabilities:** An effective way to create affordability and choice in rental housing is to prioritize people with disabilities for rent subsidies that enable access by very-low-income people with disabilities to a broader array of nonsegregated housing opportunities throughout local communities. VBPD recommends that Public Housing Authorities (PHAs) review their PHA Plans to determine if the needs of very low-income people with disabilities are adequately addressed and to add a priority in their plan for people with disabilities.

Another effective mechanism to promote housing is through Auxiliary Grants (AG). A 2007 report by the Secretary of Health and Human Resources conducted under the 2007 Appropriations Act, Item 278 C, *Auxiliary Grant Portability: A Report on the Feasibility of*

*Restructuring Auxiliary Grants for Certain CSB Case Management Consumers*, includes the following findings:

- Federal regulations allow for more flexibility in Virginia's AG program, which does not need to be limited to Assisted Living Facilities and Adult Foster Care.
- With current rates, the AG could be used as rental assistance, thereby making one-bedroom apartments affordable in most localities and two-bedroom shared apartments affordable in all localities.

VBPD recommends that the Commonwealth revise Auxiliary Grant statutes to allow seniors and people with disabilities who are found eligible for or are currently receiving Auxiliary Grants as rental assistance to choose to use the AG SSI supplement in housing types other than assisted-living facilities and adult foster care residences. This revision would be an important step forward in supporting choice, self-determination, and inclusion for individuals with disabilities.

3. **Ensure Coordination of State Housing Activities:** A Money Follows the Person Housing Task Force, created by the Secretaries of Health and Human Resources and Commerce and Trade in 2007, will develop a housing action plan in the spring of 2008 and will update it annually thereafter. This Task Force encompasses a diverse membership, including federal, state, local, and private partners. The Task Force was developed in response to the Commonwealth's MFP initiative, and, while the activities associated with this initiative are focused on rebalancing the service system from one that is institutionally biased to one that focuses on community living, the Task Force is well-positioned to have greater impact beyond the scope of MFP. VBPD recommends that this Task Force take the lead in facilitating improved, comprehensive, and coordinated strategic planning and actions across human service agencies and secretariats to reshape the structure and scope of supports to persons with disabilities statewide so that they can have choices of affordable, accessible housing that fosters independence and community inclusion.
4. **Increase Disability and Advocacy Community Participation in Planning:** To influence more successfully the use of federal housing resources, the disability community should become more actively involved in the significant state housing-planning activities such as the Consolidated Plan, the Public Housing Agency Plan, the Continuum of Care, and the Qualified Allocation Plan. To facilitate this process, more user-friendly information should be provided to the disability community both on the planning processes and on how specific housing programs are accessed and operated. For example, many federal housing programs cannot be targeted to a subpopulation of people with disabilities (e.g., people with mental illness, people with intellectual disabilities, or other specific types of disability).

VBPD recommends that individuals with disabilities who are assisted by a Public Housing Authority (PHA) participate in housing planning and discussions by being a member of a PHA's Resident Advisory Board (RAB), which provides the PHA and the residents with a forum for sharing information about the Agency's Annual Plan. Section 511 of the U.S. Housing Act and other regulations (24 CFR Part 903) require that PHAs establish

one or more RABs as part of the PHA Plan development process. The RAB's role is to assist the development of the PHA Plan and to make any significant amendment or modification to the Plan. Individuals with disabilities and the advocacy community should discuss this opportunity with their local PHA.

5. **Improve Coordinated Financing for Housing:** To promote the creation of deeply subsidized housing needed for extremely poor individuals with disabilities who cannot find access to housing otherwise, the disability community will have to challenge housing officials to improve the coordination of housing financing and possibly to change the method for allocating and distributing housing funds. For example, state housing agencies that control federal housing resources—such as Low-Income Housing Tax Credit, HOME funding, Section 8 Housing Choice vouchers, etc.—can develop a uniform application for funding that includes incentives for housing developers to combine resources and to target new housing units for people with disabilities. Some states currently require that developers that receive Low-Income Tax Credits set aside a certain percentage of new units for people with disabilities; and to ensure that these units are affordable for people with disabilities who have extremely low incomes, they encourage Public Housing Agencies (PHAs) to use Section 8 project-based vouchers to help subsidize the rents.

VBPD continues to recommend and support the development of a Virginia Housing Trust Fund using an existing, dedicated stream of state revenue. Thirty-eight states—including Maryland, North Carolina, and West Virginia—have established housing trust funds to alleviate the rising cost of housing.

6. **Amend Fair Housing Statute:** To put an end to discrimination against persons with disabilities using Housing Choice Vouchers, VBPD recommends reintroduction and passage of House Bill 1085, introduced during the 2008 session of the General Assembly, to expand the state's fair housing law to include the consideration of source of income as an unlawful discriminatory practice. In House Bill 1085, "Source of income" is defined as "*any lawful income used by a person to meet his obligation to pay for the purchase or lease of a dwelling, including payment with (i) federal funds received pursuant to public housing or Section 8 programs of the United States Housing Act of 1937, as amended; (ii) funds received from assistance made available under Chapter 1.2 (§ 36-55.24 et seq.) of Title 36; (iii) proceeds from a bequest, life insurance policy, annuity, or other like source; or (iv) funds received from child or spousal support payments.*"

## VIII. Transportation Services

### Areas of Concern for Transportation Services

The chapter detail provides information on the breadth and depth of transportation services, supports, and resources in Virginia. Cited throughout the chapter are important statistical data regarding program activities and investments in transportation systems and services. The chapter detail also provides information on areas in which the system and services have improved and describes improvement activities and outcomes. Section G focuses on the specific areas in which further improvements may be needed to move the system forward and increase affordable and accessible transportation capacity and options. The Virginia Board for People with Disabilities (VBPD) identified the issues and concerns below through a variety of mechanisms, including: (1) review and analysis of the numerous source documents referenced within and listed at the end of this chapter, (2) public comment received via the Board's six public forums held throughout the state in the spring of 2007, and (3) written comment and information provided and verified by state agencies in their reviews. The issues below are not all-inclusive, but represent those that VBPD has identified as important to systems improvement.

- 1. Fragmented Transportation Services and Disjointed Planning:** Transportation services for people with disabilities in Virginia are managed and administered in highly compartmentalized systems and the current transportation planning structures on the state and local levels are disjointed. Furthermore, planning of transportation projects/assessment of needs does not routinely take into account the needs of persons with disabilities. This service fragmentation and disjointed planning result in inadequate, unreliable, and/or inaccessible public transportation services in communities throughout the Commonwealth and significantly contributes to the dependency of people with disabilities in meeting their basic health, welfare, and safety needs. It can also thereby increase the potential for unnecessary institutionalization or prevent successful transition from institutional settings to community living.
- 2. Impact of an Aging Population:** As mentioned in the 2006 *Biennial Assessment of the Disability Services System*, the demand for increased mobility options will continue to grow as Virginians age, which will increase as the "baby boomers" mature. A need for additional transportation options for access to employment, medical care, rehabilitation, and recreational and social events has been expressed by individuals with disabilities. Furthermore, as the population grows older, there is an increased likelihood of disability, and thus the demand for public transportation services will continue to grow. There are also emerging Aging in Place initiatives that will require accessible and available public transportation. Coordination of transportation services at the state and local level will be vital to providers charged with meeting the need for service.
- 3. Service Segregation:** Special transportation services, in which each agency operates its own fleet of vehicles and transports only its clientele, are neither cost- nor capital-efficient, nor do they provide individuals with disabilities with the opportunity to be integrated with the rest of the community. While specialized transportation services are needed in some cases, many

individuals with disabilities are able to ride public transportation, whether a fixed route or demand-response service.

4. **Difficulty in Obtaining Cost Comparisons:** Because transportation costs in many human service agencies are not tracked by trip and by passenger, as it is in some rural transit systems, policymakers find it difficult to compare costs per unit of service. What is required is to build local and regional infrastructure knowledge of capital costs versus operational costs, and ways to leverage creatively local, state, and federal resources. Several rural communities, such as those in southwestern Virginia, already have a publicly funded transit system with professionally trained drivers, regular vehicle inspections, and accessible vehicles. Many of the rural privately owned transit systems can and do provide contracted health and human service transportation more efficiently than the public agencies that are currently providing these services. The experience of other states indicates that when rural transit systems serve individuals with disabilities, publicly funded health and human service agencies save money that can be allocated to other direct services benefiting persons with disabilities.
5. **Inadequate Rider Safety and Accommodations:** Safety and appropriate accommodations are a major concern for individuals with disabilities using public transportation, whether it is paratransit, demand-response, or fixed route. Concerns that have been cited include: (1) Many reported instances where wheelchair users have not been properly secured (using the wheelchair tie-downs and/or passenger restraint systems). As a result, both passengers with and without disabilities have been injured. (2) Cell phone usage by drivers has also been identified as a safety hazard. (3) Persons with visual disabilities need to have the transit stops announced so that they know where to get off the bus. This also applies to paratransit and demand-response services described earlier in the chapter. (4) There have been several reports of persons with visual disabilities who have been left at the wrong address.

In addition, although many drivers receive training in defensive driving and CPR, many individuals with disabilities feel that public transportation drivers could use more customer service and sensitivity training regarding how to assist, communicate, and interact with persons with disabilities. These individuals feel that drivers who receive this type of training have a greater understanding and respect for people with disabilities.

6. **Service Limitations and Access, Especially in Rural Areas:** Individuals with disabilities who reside in rural areas and in some urban areas continue to express a desire to participate more fully in the activities of their communities. This, however, requires reliable transportation; and restrictions on transit service areas, hours of operation, and trip purposes make medical and human service transportation provided by local public and private sector entities of very limited use to individuals with disabilities and to older Virginians.

The general lack of adequate public and paratransit services is compounded by operational and quality issues affecting the paratransit services that do exist and by a lack of stable transportation funding with, at the same time, growing demand. This fiscal instability significantly restricts a public transit provider's ability to expand services by adding routes

and/or by providing a feeder system that would connect individuals with disabilities and the general public to mainline transportation systems.

In many areas of the Commonwealth, public transit services represent either the only source of accessible and affordable transportation available or the only viable supplement to the very limited medical or human service transportation services mentioned above. As stated in the 2006 *Biennial Assessment of the Disability Services System*, an increase in evening and weekend services would allow individuals with disabilities the opportunity to pursue full-time employment, attend religious activities of their choice, enhance their education, participate in political functions, socialize, and have the freedom to live in the housing of their choice. The Federal Transit Authority (FTA) now requires the establishment of a “locally developed, coordinated public transit–human services transportation plan for all FTA programs for underserved populations.” As these plans are developed and implemented, two key benefits that could address some of the above-mentioned challenges are improved customer services and cost savings.

7. **Lack of Stoop-to-Curb Service and Related Liability Issues:** The level of assistance that is, or should be, provided by paratransit providers to and from homes and other buildings continues to be a frequent area of conflict and confusion between transportation providers and passengers with disabilities. Major challenges—both for the passenger (in terms of safety risk) and the transportation provider—arise when an individual needs stoop-to-curb or hand-to-hand service and the driver is unaware of or unable to provide this level of service.
8. **Continued Challenges with the Medicaid Transportation Brokerage System:** Consistent with public comment from users of service and with the 2006 *Biennial Assessment of the Disability Services System*, the current brokerage system for scheduling Medicaid-sponsored transportation services under contract to the Department of Medical Assistance Services (DMAS) has eliminated choice of providers and has resulted in serious incidents of unreliable and unsafe service delivery. Reports also indicate that providers of medical transportation often fail to have vehicles with proper wheelchair securement or fail to employ drivers who have training and experience in working with persons with disabilities. While DMAS has attempted to work with the current transportation broker, LogistiCare, to remedy these problems and concerns, services continue to be unreliable. Service recipients report that when they contacted LogistiCare, their complaints do not receive a response and are not consistently reported to DMAS. Under the contract with DMAS, “When a complaint is received involving transportation, an investigation will be initiated with the appropriate transportation company. A written response must be submitted to LogistiCare within 24 hours. This response should include documentation of the facts involved and any corrective action that will be taken to ensure that the problem does not occur again.” Service recipients report receiving misinformation about the complaint process and report that they call with a complaint only to find out when they call back later to follow up that there is no record of their complaint. Poor quality assurance for brokerage services continues to be a significant barrier to appropriate transportation for persons with disabilities.

9. **Inaccessibility of Related Infrastructure:** Sometimes, community infrastructure is not accessible to individuals who require the use of public and paratransit transportation services. Multiple physical barriers still exist in localities such as poorly placed and unsafe curb cuts, inaccessible emergency call boxes, lack of traffic-calming devices such as speed bumps in neighborhoods, the use of audio and other technologies for people with visual disabilities, and poorly maintained sidewalks.

National paratransit experts report a lack of priority on safe local pedestrian travel, especially in combination with the aging of the “baby boomer” generation, as one of the most significant issues that will be driving the need for improvements in accessible public transportation in the future. Localities in Virginia are required by the *Code of Virginia*, § 15.2-2223, to adopt a comprehensive plan. In 2004, the *Code* was amended to require the inclusion of a transportation element in local comprehensive plans. In 2006, the General Assembly further amended the *Code* to require the inclusion of a transportation plan: “Each locality shall develop a transportation plan that designates a system of transportation infrastructure needs and recommendations.” Pedestrian accommodations are now a required reporting standard in the above-mentioned statute. The Virginia Transportation Research Council’s 2006 report, entitled *An Evaluation of County Comprehensive Plans in Virginia*, notes that many comprehensive plans did not include bicycle and pedestrian accommodations and many of the localities that did include them did so from a recreation rather than a transportation perspective.

10. **Inadequate Coordination between Transportation and Housing:** There is a need to develop collaboration between housing and transportation stakeholders and professionals for the purposes of building the capacity of transportation and housing access and choice in communities throughout Virginia. The interdependence of housing and transportation planning on the local level in order to build a community’s capacity to promote inclusion and participation is gaining recognition; however, significant barriers still exist. In some areas, real estate developers are building more housing communities beyond the normal transit system routes. As a consequence, businesses, schools, and recreational facilities are also locating in those areas. The lack of transportation in these communities prevents an individual with disabilities from seeking employment, participating in school or community activities, or socializing there. It also reduces the choice of residential communities in which to live for citizens who rely on public transportation.

## **Board Recommendations for Transportation Services**

Transportation issues are one of the most-frequently cited barriers to full inclusion in community life by people with disabilities. Transportation is more than an access issue alone; it is also directly related to health, safety, and quality-of-life issues, as well. In addition, those issues directly relate to effective implementation of the Supreme Court decision in *Olmstead v. L.C.* Maximizing practical application of emerging technologies can profoundly affect the quality of community living for people with disabilities, including those with severe disabilities. In all aspects of their lives, people with disabilities who are unable to drive or who cannot afford an automobile must find solutions to their transportation needs. The Virginia Board for People

with Disabilities (VBPD) makes the following recommendations to address identified areas of concern and improve the quality and availability of transportation throughout the Commonwealth.

**1. Implement a Coordinated Human Services and Public Transportation Planning Model:**

A coordinated planning structure would enable the State to leverage resources better to serve all of its citizens.

The Department of Rail and Public Transit (DRPT) is taking a leadership role in current transportation coordination efforts. As described in the chapter detail above, significant groundwork has been achieved in educating localities and constituents about the improved quality of service and economic benefits that could be realized when transportation services are coordinated. DRPT has been effective in bringing to the Commonwealth important inventory, assessment, and planning components required from the various federal initiatives described earlier. As other states—such as Georgia—have proved, coordination of transportation services works, especially when implementation occurs at both the state and local levels.

Interviews with transportation-disadvantaged individuals indicate they want more transportation options, such as more-flexible schedules and more-convenient routes. VBPD recommends a coordinated transportation services' model that accounts for and examines the use of all vans and buses purchased with state funds for joint use by health and human service agencies at the local level (with an exception for school buses used to transport students to and from school). This could include, but not be limited to, vehicles used by community services boards, Area Agencies on Aging, and employment service organizations as well as other vehicles purchased with state funds. Having these vehicles accessible in evening or weekend hours would be beneficial to individuals and communities. Passenger vans and buses purchased with state funds should be used as efficiently as possible to serve transportation needs. While agency administrators may report that they need their vehicles all the time, there are typically peaks and valleys in use through the course of a 24-hour period. When these vehicles are viewed as a resource available to the community 24 hours a day and 7 days a week, their underutilization becomes apparent. In addition, one program's low usage time may fall at another program's peak usage time. Issues with respect to liability and coordination could be resolved through Memorandums of Understanding or contracts.

To the extent available, services providers should consider using the public transit systems to provide transportation for persons with disabilities as an alternative to private transport. A number of rural communities already have a publicly funded transit system. Many of these systems can and do provide contracted health and human service transportation more efficiently than the public agencies that are currently providing these services. Because the costs for transportation in many human service agencies are not tracked by trip and passenger, policymakers find it difficult to compare costs per unit of service. The experience of other states indicates that when rural transit systems provide

transportation to persons with disabilities, health and human service agencies save money that can be allocated to other direct services benefiting its citizens.

2. **Increase Public Transportation Funding:** A stable and adequate base of funding for public transportation should be established. Annual appropriations are subject to budget shifts, recessions, and changing political priorities, and thus cannot provide the dependability needed by people with disabilities, as well as others, who rely on public transportation for their basic mobility. VBPD recommends that localities include funding for public transportation as a line item in local budgets, with yearly increases to allow for expansion of services. The General Assembly should consider creating incentives for localities that do develop and expand services. Incentives could potentially be used as a match to draw federal dollars.

Because of the dependence by Virginia's public transportation programs on local funding, budgets should include capital investments in accessibility enhancements that remove barriers to individuals with disabilities. Investments in sidewalks and curb cuts, for example, can provide access to greater portions of public transportation systems, as well as offer unobstructed travel on pedestrian routes, which in some cases can provide a new option on how and where an individual can travel.

3. **Promote the Use of the Transportation and Housing Alliance (THA) Toolkit:** The Transportation and Housing Alliance Toolkit, developed by the Thomas Jefferson Planning District Commission under a grant from VBPD, includes resources, information, guidance, and technical assistance to augment a locality's ability to assess comprehensively its transportation and housing needs and capacity and to project future needs. This information can be invaluable to local planners and advocates as they work to ensure that the needs of citizens with disabilities and the aging community are adequately planned for and addressed. The Toolkit includes guidance on the use of Geographic Information Systems (GIS) to create detailed "maps" of transportation service providers and their service areas in relation to the locations of people with disabilities. The mapping can show service capacity versus prevalence of disability, and project future trends and needs. This visual map of services and service providers at the state and local levels will foster greater opportunities to improve coordination of services, to reduce compartmentalization of services, and to help service development planning to unserved or underserved areas. VBPD recommends that localities, planners, and advocates use the Toolkit as a standard practice. The Toolkit is best used as part of a planning effort for a region, community, or neighborhood. It gives planners additional tools to analyze data numerically and through mapping. It also provides a checklist to assess the study area in a variety of dimensions to evaluate the livability and efficiency of its transportation systems, housing stock, and services. The Toolkit can be used:

- As a part of a locality's Comprehensive Planning process
- As part of a community plan or transportation study
- As an element in the Needs Assessment for people with disabilities

- To help determine desirable locations for housing or services
- To evaluate proposed projects and their impact on the surrounding area

The Toolkit can be accessed at the Thomas Jefferson Planning District Commission's Web site at [www.tjpd.org/housing/thatookit.asp](http://www.tjpd.org/housing/thatookit.asp).

**4. Ensure Uniform Data Collection to Support Transportation Coordination Efforts:**

VBPD recommends that a uniform method of data collection be researched, developed, and mandated by the Commonwealth in order to enable better coordination of transportation. Because local providers are not using uniform methods of data collection, no universal method of evaluating success of a particular locality's coordination efforts is available. A state-mandated system for data collection would serve as a "yardstick" for measuring success of coordination efforts for every transit system in the state.

**5. Provide Education and Training for Human Service and Public/Paratransit Drivers:**

People with diverse disabilities are a significant portion of the ridership of human service and public/paratransit services. VBPD recommends that initial ongoing education and training for all human service and public/paratransit drivers be required on diverse disabilities, disability culture, and disability sensitivity and etiquette.

**6. Improve Quality Assurance for Nonemergency Medicaid Transportation:** The Department of Medical Assistance Services (DMAS) must hold its transportation broker, LogistiCare, accountable for correcting service shortcomings. Complaints about late pickups, drivers who are not adequately trained, misinformation, and a lack of acknowledgment of complaints, accountability, and follow through are still prevalent. VBPD recommends that DMAS and LogistiCare include on their Web sites, in a place and manner that is easy to locate, a detailed overview of the process to make a complaint and what the expected follow through should be. VBPD also recommends that DMAS conduct a comprehensive and publicly visible assessment of service needs and evaluation of service delivery and subsequently identify solutions to discovered shortcomings. Currently, a random sample of customers is surveyed on a semiannual basis. VBPD has previously expressed concern that this survey sample represents too small a percentage of transportation users to give an adequate representation of the needs and experiences of such a large and diverse customer base and provider system.

## IX. Employment Services

### Areas of Concern for Employment Services

This chapter provides information on the breadth and depth of services available to persons with disabilities seeking vocational training and employment. Cited throughout the chapter are statistical and qualitative data as well as information regarding program activities and performance indicators and information on improvements to the system and services, describing these activities and outcomes where such information is available. This section focuses on those areas that may need further improvements to move the system forward and to ensure that the needs are met for persons with disabilities seeking gainful employment. The Virginia Board for People with Disabilities (VBPD) identified the issues and concerns cited below through a variety of mechanisms, including: (1) review and analysis of the source documents referenced within and listed at the end of this Chapter; (2) public comment received via VBPD's six public forums held throughout the state in the spring of 2007; and (3) written comment and information provided and verified by state agencies in their reviews. The issues below are not all-inclusive, but represent those that VBPD has identified as important to systems improvement. Many of the issues from 2006 remain as challenges.

- 1. Inadequate State Agency Coordination:** As reported in the 2006 *Biennial Assessment*, the fragmentation of employment services among the different agencies for people with disabilities presents considerable barriers to employment. Virginia's infrastructure does not integrate employment services for individuals with disabilities in a manner that is directed by individuals with disabilities and is user-friendly. The existing system is complicated with various agencies maintaining employment-related service options for individuals with disabilities, different points of entry and application processes for services, and different eligibility requirements for various employment programs. Services available to people with disabilities, especially those with significant disabilities, are often inadequate to facilitate a person's desire to seek self-sufficiency through employment. Service capacity expansion is needed. Service capacity is a large, overarching issue that encompasses transportation, training, placement, job coaching, and worksite accommodations (such as assistive technology, workplace accessibility, and personal assistance services).
- 2. Effect of Order of Selection for Vocational Rehabilitation Services:** As allowed under the federal Rehabilitation Act of 1973, as amended, vocational rehabilitation systems may use an Order of Selection to serve individuals with disabilities when the system's resources are limited. The Department of Rehabilitative Services (DRS) has operated under an Order of Selection for several years. In 2007, due to increasing resource challenges, DRS tightened this Order of Selection further by restricting new applicant eligibility to the category of "Most significant disability." Individuals already receiving services through DRS continue to receive those services, but those who do not meet the Order of Selection criteria are placed on a waiting list. Since DRS is the primary provider of vocational rehabilitation services to persons with disabilities, the continued tightening of resources in this program is extremely problematic. Many job-seekers with disabilities have no options other than the VR system to obtain assistance in preparing for, finding, maintaining, or advancing in employment. The

Order of Selection may also disproportionately affect students in transition who may not have access to needed transition services that will help them achieve successful postsecondary outcomes if those services are not normally provided by or available from the school system. Unfortunately, without substantial additional commitment of dollars, this scenario is unlikely to change any time soon. Budget proposals pending before the 2008 General Assembly would provide additional state dollars to eliminate the Order of Selection waiting list, but it is not known at this time whether these proposals will be funded.

- 3. Concern over Potential Expansion of State Use Programs:** In October 2006, at the request of Virginia's legislative Disability Commission, presentations on State Use programs for people with significant disabilities were provided by the Department of Rehabilitative Services (DRS) and NISH. NISH is a Central Non-Profit Agency (CNA) whose mission is to create employment opportunities for people with severe disabilities by securing Federal contracts through the AbilityOne Program (formerly called the Javits-Wagner-O'Day or JWOD Program) for the network of Community Rehabilitation Programs (or Employment Service Organizations "ESOs" in Virginia). A further update was provided to the Disability Commission in the fall of 2007. State Use programs are based on the federal model that has had a long history of use in the blind community. The goal of State Use programs is to enable the Commonwealth of Virginia (as well as other government entities) to establish a system to encourage government purchases of goods and services from organizations that employ people with severe disabilities. While these employees do receive benefits such as medical insurance, annual leave, and sick leave, the individual with the disability is actually working for the ESO, which is not an employer in the competitive marketplace. In addition, the work is most often performed in a segregated work environment (sheltered workshop).

In their 1997 study, *"Sheltered vs. Supported Employment: A Direct Comparison of Long-Term Earnings Outcomes for Individuals with Cognitive Disabilities,"* John Kregel and David H. Dean of VCU-RRTC observe:

A significant amount of evidence indicates that integrated employment options improve consumer employment outcomes, cost less than other adult day programs, and generate savings for taxpayers. Benefit-cost analyses completed in the last ten years indicate that integrated employment options dramatically improve individuals' earnings and economic self-sufficiency.... Local employment programs can serve more individuals for the same amount of money, and achieve better outcomes, if they adopt an integrated employment approach.... It has been repeatedly demonstrated that supported employment programs lead to a decrease in dependence on federal disability benefit programs, a reduction in the need for costly alternatives such as workshops or activity centers, and an increase in the taxes paid by workers with disabilities.

There is no reason to believe that this information is any less valid in 2008 than it was ten years ago.

Most states have increased the availability of individual supported and customized employment options and moved away from segregated sheltered workshop programs. While

the Virginia Board for People with Disabilities (VBPD) has not recommended closing current sheltered workshops in Virginia, it does not support the expansion of segregated employment programs for people with disabilities. VBPD wants to avoid an increase in the number and size of segregated employment programs and the long-term maintenance of the programs. Expansion of State Use would further solidify the segregated model of employment in Virginia and potentially result in more individuals being directed toward such settings rather than toward integrated, competitive supported employment. VBPD understands that movement toward an expansion of State Use in Virginia is currently on hold. Any further development towards State Use should be closely monitored, with advocates both for and against the concept involved in all discussions.

4. **Fear of Benefits Loss:** A continuing concern for many Virginians with disabilities who choose to work is the potential loss of Medicaid eligibility if their earnings are too high. As a result, many either do not seek employment or limit their hours or actual wage level. Several individuals commented about their fear of losing benefits or the need continually to alter their work schedules so that they would not exceed the number of hours worked and then lose their benefits. When pay periods are inconsistent and three checks are received in a month rather than two, for example, a person's benefits are put at risk. The Medicaid Buy-In Program, Medicaid Works, was implemented in January 2007, permitting higher income and resource levels while ensuring continuation of needed health-care coverage, thus providing an opportunity and incentive to seek gainful employment. As of December 2007, however, only 14 individuals had enrolled in the program. As shown with the low usage of other work incentives and the complexity of the programs, it has proven difficult to educate people with disabilities and disability professionals across numerous state agencies about Medicaid Works. It has been shown that educational programs targeting this audience can have an impact. Another work incentive, the 1619(b), allows Medicaid recipients to work and keep Medicaid (with a lower threshold than Medicaid Works). As a result of intensive SSA work-incentive training to state agencies and disability professionals, people with disabilities and families of people with disabilities (sponsored by the Virginia Board, DMAS and DRS), there has been a 40 percent increase in use, from 1,441 in 2003 to 2,018 in 2006.
5. **Financial Disincentives to Employment:** The caps on earned income and the resources that can be saved by individuals with disabilities serve as a clear disincentive to employment. Participation in gainful employment can reduce a person's benefits or other resources that support his or her ability to continue to live and work in the community. In all areas—from housing, to health insurance coverage, to personal care—substantial financial disincentives affect individuals with disabilities who seek self-sufficiency through competitive or community-based employment. (One example is the low Personal Maintenance Allowance reported in an earlier section.) There are also financial disincentives for providers who receive more revenue if individuals with disabilities do not work (because they cannot be paid for a service that is not being provided while the individual is at work), resulting in conflicts between day support and work opportunities and the real potential that consumers can be discouraged from working. Financial disincentives are often the unintended consequence of the complexity of dated and conflicting federal, state, and local disability policies across programs and agencies. Often these disincentives cause people to lose the

services and supports they require to achieve independence and self-sufficiency. For people with disabilities on SSI or SSDI, few take advantage of the SSA work incentives that are available. These work incentive programs are complicated and difficult to understand, and require cumbersome paperwork following qualification, which limits their use by professionals, people with disabilities, and their families.

- 6. Inequitable and Inaccessible Services:** The current service delivery system, including the Virginia Employment Commission (VEC) One Stop Services System established under the federal Workforce Investment Act (WIA), still does not provide equal access to services to people with disabilities, a requirement of the WIA. This issue remained unchanged from comments made in 2006. The system is underutilized by people with disabilities because of lack of physical and program accessibility, lack of training on specialized equipment, and inadequate training of One Stop staff members, who often are inadequately informed about the unique employment and support needs of individuals with disabilities.

The Virginia Workforce Network has made great improvements to the One Stop system. As previously reported, the Network has implemented the Disability Program Navigator (DPN) Program with 13 DPNs serving the 16 One Stop Workforce Centers throughout the Commonwealth. The Charlottesville Workforce Center opened in 2007 with a consortium of local and state disability agencies and organizations. Because it is both physically and programmatically accessible to people with disabilities, this facility will serve as a model for all of the One Stops in Virginia. According to the Governor's Office on Workforce Development, the DPNs are working with all of the One-Stops to obtain updated accessibility surveys and to implement the recommendations of those surveys to make all Virginia One Stops fully accessible. Unfortunately, there is no timeframe or written plan within which to complete this assessment, and the grant that pays the DPN salaries concludes in 2008. At the time of this report, no new source of funding to preserve these positions had been identified.

- 7. Inadequate Focus on Career Development versus Job Placement:** People with significant disabilities who receive vocational training and job placement continue to report that they experience a "one size fits all" mentality. Numerous individuals who had either received vocational rehabilitation (VR) services in the past or were currently receiving services attended the six public forums on the Biennial Assessment hosted by the Virginia Board for People with Disabilities (VBPD) in the spring of 2007. The attendees' comments were consistent with those received in 2006, noting dissatisfaction with employment and training services and feeling that they were being geared to low-level jobs not consistent with their abilities or employment goals. This complaint related to jobs found through both the One Stops and the VR system. Individuals felt that their abilities and strengths were not assessed, that they were trained for traditional jobs (office work, food services, janitorial), and were sometimes trained for jobs that did not exist in their locality or region. They noted the need to have an advocate with them to obtain the services they needed. Other issues cited in public comments were that once "placed" in a job they had no opportunity for advancement. Individuals who spoke out at the public forums also felt that their choices were frequently not respected and that creative opportunities for employment, such as self employment

enterprises, were discouraged. Consumer-directed employment-support services, which will be available under the Money Follows the Person demonstration initiative, will be a positive development with respect to ensuring consumer choice and increased opportunities.

8. **Lack of Reliable Transportation to Job:** As noted in the chapter on Transportation, transportation or the lack of it affects all activities of daily life, including employment. If an individual does not have reliable transportation, he or she cannot keep a job. If an individual is receiving vocational rehabilitation services, he or she may receive transportation services during periods of assessment, training, and job development. Once the individual is employed, however, lack of transportation can be a significant obstacle to maintaining employment. The Board agrees with the statement in Virginia's *2007 Comprehensive Cross-Governmental Strategic Plan to Assure Continued Community Integration of Virginians with Disabilities*. "Transportation is basic in the integration into and survival in community living for individuals with disabilities. . . . Transportation of all kinds must be consistently available, affordable, accessible, reliable, safe, and meet the needs of individuals with disabilities throughout the Commonwealth."
9. **Challenges with Transition Services for Students with Disabilities:** Although federal law identifies the local school division as the primary entity responsible for transition services for students with disabilities, the participation of other local and state agencies—including vocational rehabilitation agencies, community services boards, and case managers—can be critical to successful movement from high school to postsecondary options, such as further education, employment, and independent living. Public comment continues to denote dissatisfaction with regard to how often and when the Department of Rehabilitative Services (DRS) becomes involved in the transition process for students. Even though DRS has counselors focused on transition, there appears to be miscommunication or perhaps a misinterpretation of policy as to when DRS can or should serve students. The current Order of Selection under which DRS is operating also results in much greater challenges for students with disabilities who could benefit from services offered through vocational rehabilitation.

## Board Recommendations for Employment Services

Employment for many people with disabilities is critical to ensuring their full integration into community living, self-sufficiency, and independence. The Virginia Board for People with Disabilities (VBPD) makes the following targeted recommendations to improve the availability and accessibility of appropriate employment services and opportunities for people with disabilities in the Commonwealth.

1. **Provide Greater Career Options and Opportunities for People with Disabilities:** VBPD recommends that the Commonwealth expand, and make more flexible, training, coaching, placement, assistive technology, and other workplace accommodations and career development services. Employment training should include job placement that is part of a career path. One important option is Customized Employment, which is a process for individualizing the employment relationship between an employee and an employer in ways that meet the needs of both parties. It is based on a match between the unique strengths,

needs, and interests of the job candidate with a disability, and the identified business needs of the employer or the self-employment business chosen by the candidate. Self-Employment is another creative option that can provide opportunities for employment for people who have few other options, such as those in rural settings, those who experience significant disabilities, have limited transportation options, and other barriers to employment in a traditional setting. These options should be expanded in order to provide a variety of career choices, especially for people with significant disabilities. VBPD believes that customized, supported, and other integrated employment options should be the focus of Virginia's job training and employment efforts, rather than the expansion of State Use or segregated-employment programs.

2. **Eliminate Barriers to the Utilization of Work Incentives:** Although there has been some increase in the use of work incentives, such as the 1619(b) (Medicaid While Working), most Social Security Administration (SSA) work incentives are underutilized. In addition, the Medicaid Buy-In program (launched in 2007 with a higher threshold for earnings and savings than 1619[b]) has resulted in 14 enrollees for its first year. VBPD recommends ongoing training and technical assistance for staff members in state and local agencies that provide services to people with disabilities, particularly local social services agencies and public school transition personnel, who may be the first point of contact for many individuals with disabilities. Increased coordination among state agencies and federal Work Incentive Projects is needed in order to inform and encourage beneficiaries to enroll in work incentive programs.
3. **Provide Sufficient Funding to Eliminate Vocational Rehabilitation Waiting Lists and Lift Order of Selection:** The Department of Rehabilitative Services (DRS) is currently operating under Order of Selection with only one category open. The Department for the Visually Impaired (DBVI) currently has all categories open but an Order of Selection has been imposed at this agency in the past. VBPD recommends that sufficient state general funds be provided for vocational rehabilitating (VR) services to supplement flat federal funding. The Board also recommends consideration of additional resources specifically for implementation of transition services by VR to all students with disabilities who require such services in order to meet postsecondary school outcomes for education or employment.
4. **Explore Funding Resources to Ensure That the Disability Program Navigator Initiative Will Continue:** The two-year U.S. Department of Labor grant that provided funding for 13 DPN staff members to support the 16 One Stop Workforce Centers throughout the Commonwealth will end in June 2008. As of February 2008, it is uncertain whether the Commonwealth will receive funding to continue the program. The Board recommends that state and federal funding resources be explored for the DPN Initiative to ensure that physical and programmatic accessibility and employment services for people with disabilities seeking job assistance through the One Stops will continue.

## X. Advocacy and Information Resources

### Areas of Concern for Advocacy and Information Resources

This section provides information on advocacy resources and services available to persons with disabilities. While this list is not all-inclusive or exhaustive, it does focus on specific areas where further improvements may be needed to advance advocacy in the Commonwealth. The Virginia Board for People with Disabilities (VBPD) has identified the following concerns through a variety of mechanisms, including: (1) review and analysis of the numerous source documents listed at the end of this chapter, (2) public comment received via six public forums that VBPD held throughout the state in the spring of 2007, and (3) written comments and information provided and verified by state agencies in their reviews. VBPD has identified the following issues as essential to the improvement of both individual quality of life and the success of systems overall:

- 1. Challenges in Obtaining Information about Rights and Available Services:** Individuals and their families continue to report a lack of awareness and inadequate information regarding the programs and services that may be available to them. This extends throughout the lifespan and across agencies, programs, and services. Comments made at VBPD's 2007 public comment events, and through numerous constituent contacts by individuals with disabilities and their families, indicate that individuals with disabilities and their family members encounter significant difficulty in learning about their rights or services to which they are entitled, even when the provider has the legal responsibility to provide such information. These individuals report that they are unable to receive clear answers or receive multiple, sometimes conflicting, responses, often from the same entity. Comments also indicate that, too often, agency staff members (local and state) only know or share information about their own agency's services, and do not know about other disability resources. Families report that once their children leave secondary school, they have no access to a single information source on services and supports.
- 2. Lack of Disability-Friendly State Web Sites:** In response to a request by the Office of the Governor, VBPD specifically queried participants at its 2007 public comment events about their experiences with state agency Web sites as well as their perceptions of site usefulness and accessibility. Agency Web sites were described as being very challenging to navigate, sometimes lacking accessible formats. Frequent complaints were that the information most important to them—available services, eligibility criteria, and application process—was very difficult to find and that the language used was too bureaucratic or technical. Two central concerns voiced by participants were: (a) the quality and usefulness of Web site information, and (b) the lack of access to computers for many persons with disabilities (a "digital divide"). One comment summarized the first concern: "I don't care about the mission statement or what the Commissioner thinks. What does your agency do? How do I figure out whether I am eligible? Use simple language." The second concern related to income level and age differences. Another common complaint was the absence of contact information to a person who could help answer questions. In addition, comments indicated that, too often, Web site information is not kept current. One region-specific problem was noted: that downloading

information was difficult in rural areas where only the slower, dial-up connections were available, rather than faster broadband connections. In conducting research for this *Assessment*, VBPD itself found that some state agency Web sites had out-of-date, undated, or undocumented information. VBPD also found that the reliability of search functions was extremely variable; it was often difficult to locate specific reports on agency Web sites, even knowing the title and date of the report. It should be noted that the Department of Mental Health, Mental Retardation and Substance Abuse Services recently updated and improved its Web site. The Disability Service agencies under the leadership of the Department of Rehabilitative Services (DRS) have also made improvements, but all state agencies need to do more work in this area.

3. **Need for Increased Disability Advocacy and Awareness Training:** Individuals with disabilities, family members, and advocates note the need for increased training opportunities for themselves, for professionals, and for providers. Problems of basic accessibility and reasonable accommodation continue to exist in nondisability-friendly arenas such as Board of Supervisor meetings, Parent Teacher Association (PTA) meetings, and public forums held by state and local agencies. This is often attributed to lack of knowledge regarding the needs or resources available, not to a lack of desire to provide accommodations. Participants at Virginia Board for People with Disabilities (VBPD) public comment events statewide described encountering barriers on a daily basis that reflect the absence of consideration of persons with disabilities: For example, school personnel continue to have lowered expectations for students with disabilities; use accessible restrooms for storing supplies, thereby infringing on the space needed for wheelchair access; pile snow into accessible parking spaces, thereby blocking access; or fail to provide interpreters for deaf or hard-of-hearing hospital patients, leaving them without vital communications support in emergencies.
4. **Inadequate Individual Advocacy Resources:** Although the Virginia Office for Protection and Advocacy (VOPA) has the most significant funding for rights protection in the Commonwealth, this agency's services are limited by distinct program eligibility criteria, federal funding restrictions, and the requirement to establish annual program priorities. These factors limit the number of persons served and the issues addressed. Most public or private nonprofit organizations, even those focused on advocacy, do not have the staff or funding resources sufficient to provide individual-based advocacy. This situation has not changed since the 2006 *Biennial Assessment*, and is unlikely to change unless substantial new federal or state resources devoted to advocacy are made available. The need for advocacy assistance was poignantly voiced by participants during VBPD's 2007 public comment forums. Individuals reported being "ground down" by the system, feeling like they are in a "war zone," and being "exhausted" by efforts to obtain services to the point of not having energy left for advocacy.
5. **Lack of Reliable Data on Long-Term Systems Needs:** As noted earlier, public comment received by the Board emphasized the importance of advocacy to policymakers and decision-makers that accurately projects actual service needs, both current and long-range. Advocates expressed particular frustration with the lack of reliable data on the number of persons with disabilities and their families. Such data is essential to the accurate projection of needs for the next five to ten years.

The Virginia Board for People with Disabilities (VBPD) shares these concerns. While data regarding the needs of persons with disabilities, programs available to them, numbers of persons served, and outcomes are gathered by numerous agencies, data collection processes are extremely varied by agency. Further, because of legal requirements, data often cannot be shared among agencies, other than in an aggregate manner. The lack of uniformity in data collection, analysis, and reporting—not only among agencies, but sometimes within the same agency from one year to another—makes it difficult to plan and assess needs accurately. VBPD recognizes that data collection is made more complex by varying and ever-changing requirements at the federal, state, and local levels. The result, however, is that information regarding the needs of individuals with disabilities is often inconsistently maintained and data on waiting lists (for Home and Community Based Waivers and all other programs and services) are fluid and do not necessarily accurately portray either short- or long-term needs. All of these factors make it difficult for the General Assembly and the Governor to make informed decisions about long-term services, supports, and appropriate resource allocation.

- 6. Need for Increased Use of Person First Language:** Statutes, regulations, policies and practices in Virginia use antiquated and sometimes offensive language, albeit not by intent. The Commonwealth should be a leader in using language that is respectful of persons with disabilities and conveys that they are a “person first.” One noteworthy model of language change in state regulations are the revised *Rules and Regulations to Assure the Rights of Individuals Receiving Services from Providers of Mental Health, Mental Retardation and Substance Abuse Services*, 12VAC35–115–10 et seq., issued in the fall of 2007. The Department of Mental Health, Mental Retardation and Substance Abuse Services is to be commended for its adoption of person-first and person-centered language throughout this regulation. Other recent positive developments are reflected in numerous bills in the 2008 General Assembly, including the proposal that the term “mental retardation” be changed to “intellectual disability.” This language reflects a national trend to focus on the individual rather than the person’s disability category or diagnosis.

## **Board Recommendations for Advocacy and Information Resources**

Individuals with disabilities and their families need access to accurate and up-to-date information and in order to make decisions about health care, education, employment, and other areas of daily life. Many advocacy resources exist and technology has vastly improved access to information. More challenging than information access, however, is the availability of individual advocacy resources, legal representation when needed, and training on rights and responsibilities. The Virginia Board for People with Disabilities (VBPD) offers the following broad recommendations with respect to improving these opportunities around the Commonwealth.

- 1. Provide Continued Education and Training to Individuals with Disabilities and Their Families:** VBPD recommends continued and ongoing investment by agencies and organizations tasked with providing advocacy and information resources to individuals with disabilities and their families. This is a never-ending need as laws, regulations, policies, and practices change. Access to information and training is important for individuals residing in

the community, but it is also important that individuals with disabilities residing in institutions, their families, and surrogate decision-makers be educated about rights and choices about community living options, as such individuals who may be the least likely to be informed about community programs and services available to meet their needs. Agencies and organizations must carry out their responsibility, legal and moral, to inform individuals with disabilities, family members, and advocates, of their rights in an ongoing, accessible, user-friendly manner. Specific, creative, and proactive strategies must be developed and undertaken to ensure that consistent, reliable, and accurate information is provided on legal and civil rights, best practices, and community opportunities.

2. **Increase Involvement of the Disability Community in Planning and Assessment of Services:** With the establishment of a senior advisor position in the Governor's office and the establishment and work of the Office of Community Integration, also in the Governor's office, much progress has been made with respect to involving the disability community in planning and service development. Likewise, agencies such as the Department of Mental Health, Mental Retardation and Substance Abuse; the Department of Medical Assistance Services; and the Department of Education—all of which are involved in various system transformation efforts—have demonstrated a strong commitment to involving individuals with disabilities and their families in planning work groups and task forces. This type of involvement, however, is generally limited to agencies that are directly responsible for disability services and/or programs. The work of numerous other state and local agencies also directly affects individuals with disabilities and their families. VBPD recommends that all state and local agencies facilitate meaningful participation in program and service planning by all those who are affected by them. These individuals need to be involved from the very onset of service system planning to ensure that their voices are heard and their needs are met. Each agency should conduct (or continue to conduct) periodic, routine assessments of citizen satisfaction—including input from individuals with disabilities and family members—with respect to their involvement in planning, implementing, and receiving services.
3. **Improve Reliable Data Collection and Assessment:** VBPD recommends that, from a disability service standpoint, agency partners strive to identify accurately how many need a given service, await services, are receiving some but not all the services they need, and other important planning factors. We realize that this would be a large and difficult undertaking and recommend that, as a first step, data collection practices in other states be reviewed to determine what state, if any, may have successfully addressed this challenge. Virginia has recently been awarded a grant to implement a "State Profile Tool" that will ensure that long-term care activities can be monitored and that the Commonwealth can assess its progress toward improving community supports. The tool is anticipated to be developed by April 2009. This grant, in concert with the Systems Transformation and Money Follows the Person Demonstration, will substantially improve the service delivery system for seniors and individuals with disabilities.
4. **Promote Common Ground:** While Virginia's public and private disability advocacy organizations cannot be expected to agree on all issues, it is essential that advocates come

together when they can to identify common concerns and pool their individually limited resources to advocate for systems change. VBPD has worked to enhance its partnerships with other agencies and organizations and recommends continued expansion of coalition-building to identify and address areas of common concern.

5. **Improve Accessibility of State Agency Web sites:** VBPD recommends continued work on improving the accessibility of state agency Web sites. The efforts initiated through the Governor's office are an excellent start, but more work is needed to develop user-friendly Web sites. In addition to the Web sites themselves, the content should be provided in multiple formats, to allow individuals with disabilities access to information utilizing special software. VBPD further recommends that state agencies ensure that print materials posted on Web sites are available in alternate formats.
6. **Need for Additional Advocacy Resources and Increased Commitment to Advocacy:** Individuals with disabilities need advocacy services, which are often either costly or difficult to access. Many programs (such as the Virginia Office for Protection and Advocacy) have very strict eligibility requirements; others have limited funding and staffing (such as Centers for Independent Living). VBPD recommends that local and state agency staff members, including case managers, consider individual advocacy to be an integral part of their job. Often heavy workloads and conflicting priorities affect the willingness and ability of agency staff members to advocate. Yet these services are important to ensuring that the voices of individuals with disabilities are heard and respected throughout the service delivery process.

## XI. Emergency Preparedness

### Areas of Concern for Emergency Preparedness

This chapter detail provides information on the current state of emergency preparedness services in Virginia. Cited throughout the chapter are important information and data regarding state agency programs and activities. Here the reader will also find information on improved systems and services and improved activities and outcomes. This section focuses on the specific areas in which further improvements may be needed to move the system forward, particularly with respect to meeting the needs of persons with disabilities. The Virginia Board for People with Disabilities (VBPD) identified the following issues and concerns through a variety of mechanisms, including: (1) review and analysis of the source documents referenced within and listed at the end of this chapter, (2) public comment received via VBPD's six public forums held throughout the state in the Spring of 2007, and (3) written comment and information provided and verified by state agencies in their reviews. These issues are not all-inclusive, but represent those that VBPD has identified as important to systems improvement.

- 1. Continued Challenges with Respect to Including Individuals with Disabilities in Planning and Preparation Activities:** The Community Integration Advisory Commission and the Virginia Emergency Planning Delegation, both of which attended the June 2006 *DHHS/Homeland Security Working Conference on Emergency Management and Individuals with Disabilities and the Elderly* (described later in this chapter) agreed that there were many challenges to be addressed regarding the inclusion of individuals with disabilities in planning, training, and responding in the event of an emergency. There are concerns that individuals with disabilities and advocacy organizations have not been systematically engaged in discussing the contributions they can make in emergency planning and have not typically been engaged as active participants in disaster-response training, planning, and exercises at the state, regional, or local levels. Until fairly recently, entities with emergency planning responsibilities have not partnered with disability organizations. There have been only limited opportunities to bring experienced emergency response and public safety personnel together with individuals with disabilities to ensure that both communities share their expertise and lessons learned about direct evacuation and sheltering. Integration of individuals into the emergency prepared processes in programs such as the Community Emergency Response Team has historically not occurred, although efforts are underway to do so at the state, regional, and local levels.
- 2. Need for Improved Shelter Management and Better Definitions:** It is critical to identify the availability of accessible shelters that can meet the needs of persons with diverse disabilities during and after an emergency event. Shelters used for the general population are often not accessible to individuals with disabilities nor are they compliant with the Americans with Disabilities Act (ADA). Red Cross shelter standards for accessibility are unclear. There has been no mapping of shelter locations for the general public or individuals living in the community. Though there are some discussions with Medicaid regarding the development of plans for persons residing in institutions, it is unclear whether discussions and planning are underway to address the need of individuals with medical needs who are

living in the community. Clarity is needed regarding what advance agreements are in place with transportation providers, home health-care providers, and the appropriate role of volunteers who may have special knowledge about people with disabilities. General population shelters that do not accommodate those with special medical needs will result in additional burdens for families who may have to relocate from shelter to shelter several times or be separated from family members.

3. **Lack of Adequate Transportation Options:** A continuing gap and critical need that must be addressed is evacuation transportation for persons with disabilities living in the community and in congregate-living situations, such as group homes. Even if appropriate shelter facilities are available, individuals with disabilities must be able to reach those facilities.
4. **Need for Education on Emergency Planning:** Ongoing education of family members, individuals with disabilities, and the general public is needed to ensure appropriate planning for the supports that an individual with a disability will need in an emergency situation. Many citizens do not have their own personal emergency plans. It is even more critical to have such a plan, however, when there is an individual or family member who has special needs with respect to shelter, medical care, and medication administration, or a need for personal care and support.

## **Board Recommendations for Emergency Preparedness**

The Virginia Board for People with Disabilities (VBPD) is pleased to have had the opportunity to work with the various state agencies and departments, as well as the Office of Community Integration, on a variety of emergency planning workgroups and task forces. VBPD felt that a chapter on Emergency Preparedness and Planning within the *2008 Biennial Assessment* was an important addition. The broad recommendations below are consistent with and support the recommendations of the many groups that have been meeting over the last two years to ensure that our citizens with disabilities are safe, have proper medical and other care, and are treated with respect and dignity during an emergency situation.

1. **Implement Community Integration Advisory Commission (CIAC) Recommendations:** VBPD recommends implementation of the CIAC recommendations delineated in Section C of this chapter.
2. **Involve Individuals with Disabilities in Planning:** It is important to ensure full representation of individuals with disabilities and their families in emergency preparedness and planning activities. VBPD recommends that the Virginia Department of Emergency Management (VDEM) provide guidance to state and local agencies related to how to accomplish meaningful participation. VDEM should consult with disability services agencies to ensure that they are able to provide accurate information on the requirements of the Americans with Disabilities Act and can advise localities on how to: (1) provide reasonable accommodations to people with disabilities, and (2) access the support and resources they need to ensure inclusion of this diverse population in all local, regional, and statewide planning activities and exercises.

3. **Enhance Shelter Accessibility:** VBPD supports implementation of the recommendations detailed in this chapter regarding accessible shelters. VBPD believes that planning for shelters should include an emphasis on supporting families so that they can remain together. In addition, there must be enough sheltering facilities that are equipped with, or able to accommodate, the specialized equipment and resources of individuals who have complex medical needs (i.e., the need for refrigeration, medication planning, backup power sources, and so on).
4. **Ensure Adequate Transportation in Emergencies:** VBPD recommends that the Virginia Department of Emergency Management (VDEM) and its partner agencies carefully review transportation service gaps for individuals with disabilities living in the community or in congregate settings. When developing transportation and evacuation plans, emergency planners need to account for the transportation needs of citizens with disabilities (and the elderly). It is also critical for congregate settings to have adequate plans for emergency transportation and evacuation, and that these plans be updated at least annually. VBPD also recommends that VDEM review current capacity for evacuation transportation and work with localities to develop and/or provide training to drivers who will be evacuating persons with disabilities and their family members.
5. **Identify and Implement Best Practices from Other States:** VBPD recommends that the Department of Emergency Management, the Office of Commonwealth Preparedness, the Virginia Department of Health, and other relevant agencies review best practices in emergency preparedness for disabilities, as identified by the federal government and as practiced in other states. Issues of particular concern, as noted above, are shelter, transportation, and planning for medication. The Department of Medical Assistance Services should determine whether other states have workable systems for ensuring that medication supplies are stocked and available in the event of emergencies, that needed prescriptions are readily available, and that insurance company (public and private) policies regarding medication refills do not pose a barrier to medication access during emergency situations.
6. **Promote Emergency Planning Efforts and Training Opportunities:** VBPD recommends direct outreach and marketing through media or other avenues to individuals with disabilities, the elderly, and family members who may not be aware of state, regional, and local services or resources. While emergency planning information tips and tools are provided on a variety of state agency Web sites, many citizens may not know where to look for this information or may not have Internet access. Information should be available, on request, in alternate formats and reasonable accommodations should be provided to ensure communication and information access to individuals with disabilities.

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\*Many thanks to these Board members who served on the Board's *Ad hoc Biennial Assessment Committee*, which provided review and guidance throughout the development of the Assessment Report.

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