

I. Key Findings and Board Recommendations

During our lives, most of us will experience some type of disability—either permanent or temporary. As aptly stated by Connie Garner, former Policy Director of the U.S. Senate Health, Education, and Labor Committee, at the 2011 Disability Policy Conference in Washington, D.C., **“None of us knows who we will be tomorrow.”** The average citizen often assumes that a comprehensive system of services and supports is, or will be, in place in the eventuality of a disability.

With that thought in mind, the Commonwealth of Virginia is at a major turning point. The potential exists to transform its services for citizens with intellectual and developmental disabilities; however, it is important to keep in mind that decisions on disability policy and funding are primarily political in nature.

Over the past decade, despite the recent deep economic recession from which the nation and the state are just beginning to recover, Virginia has remained relatively well-off financially. In *Virginia Compared to Other States* (http://jlarc.state.va.us/pubs_rec.htm), the Joint Legislative Audit and Review Commission (JLARC) reports that Virginia has ranked among the top ten states in per capita income since 2004. In contrast, Virginia consistently ranks near the bottom among the states in its level of “fiscal effort” on behalf of services for individuals with intellectual and developmental disabilities (ID/DD). The *State of the States in Developmental Disabilities* (www.cu.edu/ColemanInstitute/stateofthestates), a well-respected annual national study, defines fiscal effort as how much a state spends for both community supports and publicly or privately operated institutional services, excluding nursing facilities, per \$1,000 of total state personal income. Using that measure, it ranked Virginia as 45th in fiscal effort for all ID/DD services during 2004, 2006, and 2009. Virginia’s fiscal effort for community-based ID/DD services alone ranked 46th in both 2004 and 2006, and in 2009, the state ranked 43rd.

The **2011 Assessment of the Disability Services System in Virginia** examines how, or whether, services have changed since the **Virginia Board for People with Disabilities** (referred to hereafter simply as “the Board”) last assessed the system in 2008 and calls attention to the substantial work that still lies ahead. In conducting its assessment, the Board found that numerous positive steps have been taken to serve people better, but some barriers to change remain. Individual chapters cover early intervention, education, employment, Medicaid, community supports, institutional services, health care, community housing, transportation, and emergency preparedness. Each chapter describes positive steps taken to serve individuals better, service gaps, complexities of service access and delivery, and barriers to improvement.

This summary focuses on the broad-based disability services system as a whole. Its key findings draw on information and data supplied by the agencies that provide those services for

individuals with disabilities, and its recommendations address significant service gaps, barriers, or issues. The Board's recommendations target systemic improvements to better support individuals with disabilities across their lifespans. For this summary, selected data is drawn from the individual assessment chapters on various services, but it is not fully repeated, and those chapters should be consulted directly for details including source references. To expedite searches for these details, the full assessment, including all of the chapters listed above and useful appendices, can be found on the Board's website (www.vaboard.org/reports.htm).

As a lens for examining the current service system, the Board developed the ***Benchmarks for Evaluating Public Policy in Virginia*** listed below. The purpose of these benchmarks is "...to inform future policy and strategic investments in community supports and infrastructure that will enable Virginia's citizens with disabilities to return the Commonwealth's investment through increased independence, educational achievement, economic self-sufficiency, and community or civic engagement."

Benchmarks

Individuals with disabilities have access to and receive flexible, person-centered services and supports that:

- ✓ Provide a single point of entry that is not disability specific;
- ✓ Offer choice and maximize personal decision-making;
- ✓ Are available no matter where the individual lives and are effective, timely, and reliable;
- ✓ Promote high expectations and individual potential and strengthen families;
- ✓ Continue as needed across the lifespan; and
- ✓ Have sufficient oversight to ensure health, safety, and welfare and to prevent exploitation, fraud and waste.

In developing these *Benchmarks* and the *2011 Assessment of the Disability Services System in Virginia*, **the Board recommends and advocates for implementation of the following core system features:**

- Publicly funded supports for children and adults with disabilities and their families must be **front-loaded to provide services as soon as indicated at appropriate levels**, reducing services needed over the individual's lifespan and maximizing the individual's opportunities to "give-back" to the community at large.
- Further, in order to thrive, individuals with disabilities must receive services and supports appropriate to their needs in **inclusive, integrated community settings** and not be segregated from their fellow citizens.

- **Accountability for service quality and effectiveness** is essential not only to ensure individual outcomes and safety but also to ensure sound use of taxpayer funds. A commitment to **meaningful, consistent oversight** is therefore required.
 - State leadership should set performance expectations for agencies that include reasonable timeframes and are measurable, realistic, and person-centered, with both positive and negative consequences for those agencies based on their results.
 - Both the performance expectations and outcomes should be published and available on Secretariat and agency web sites.
- To ensure accountability, **state agencies must have the capacity and a mandate for identifying, collecting and analyzing meaningful outcome data for each program or service**. Capacity building involves adequate manpower, staff training, and technology. In conducting research for its assessment, the Board found that state agencies all too often lacked reliable data on even simple measures, such as unduplicated counts of individuals served by a program. Many agency programs have inadequate quality assurance processes in place to ensure that data collected is accurate and timely, and too often, outcome data are not available on agency websites. Some data, even in recent reports and documents, were several years old, and other data were not available for a state fiscal year because they were based on the federal fiscal year. Like the private sector, state agencies need to develop reliable, valid data on both individual outcomes and expenditures. Outcomes should address whether the services that they provided were appropriate, timely, and made a difference in individuals' lives.

In the opinion of the Board, adherence to the *Benchmarks* listed above and the adoption of these core system features when developing or expanding disability services, including their integration into decisions involving **contract services**, can significantly improve community inclusion and integration throughout the Commonwealth. More prudent use of scarce taxpayer funds will also result.

Lifespan supports should begin at initial diagnosis, and ideally, screening for developmental delays or other disabilities should occur as part of routine medical screening as an infant or child ages. Early receipt of needed services at adequate levels can reduce functional impairments later in life, thereby, promoting more self-sufficiency. Despite some recent improvement, available data shows that Virginia still continues to perform poorly and lags behind other states in the **identification of infants and toddlers needing early intervention services** (also known as “Part C services”) from birth to age three, especially in the first year of life. Since 2005, Part C improvement plans have called for Virginia to contact states serving a high percentage of children from birth to age one to determine those states' effective outreach practices, but this has still not been completed.

The Board's 2006 assessment addressed this issue, and it is still a concern. This lack of early identification was also cited by JLARC's 2009 *Assessment of Services for Virginians with Autism Spectrum Disorders*. The Commonwealth's poor performance in early identification and

concurrent barriers to accessing early intervention, such as local variability in the scope and availability of services and the cost of providing intense intervention at very early ages, mean that more intensive services will be needed for children to “make up for lost time.”

The number of children identified through the Part C early intervention system has also been disproportionate to the significant amount of money that has been infused into that system. Between state fiscal years (SFYs) 2006 and 2009, general fund appropriations to the Part C system more than doubled, from \$3,125,000 to \$6,861,000. From SFYs 2006 to 2010, however, the “Annualized Count” of eligible children entering the Part C system increased only by 31.4 percent, from 10,212 to 13,421. The Department of Behavioral Health and Developmental Services (DBHDS) has long recognized the need to better review Part C expenditures to determine whether sufficient funds are being directed to early intervention Child Find efforts, but that determination has not occurred, and the reasons for lack of review are unknown.

The percentage of children with disabilities enrolled in Head Start under a Part C Individual and Family Services Plan declined from 15 percent in federal fiscal year (FFY) 2008 to nine percent in FFY 2010. No explanation is available for this decline, but analysis would be useful to determine if more of these children are being served in the Part C system as opposed to Head Start. Child Find, however, was not addressed in the *Report on Virginia’s Part C Early Intervention System* submitted to the General Assembly by DBHDS in 2010.

Positive developments in early intervention have occurred since the 2008 fiscal year. After three years of being in the “needs assistance” category, Virginia’s program was found to meet federal requirements. The newly established **Medicaid Early Intervention Program** provides an important funding source for early intervention services that increases revenue to the system, facilitates access to needed interventions, and improves provider rates, which could lead to improvement in the number and quality of available providers. The federal *American Recovery and Reinvestment Act* (ARRA) has also provided new funding for the system over the past two years, but the end of this funding on September 30, 2011, is likely to affect fiscal stability.

As is the case with the disability services system as a whole, obtaining accurate data and tracking monies spent by service or program have been challenges for Virginia’s early intervention system. Some improvements to program, revenue, and expenditure reporting requirements, however, have been made, such as no longer allowing aggregate expenditure reporting by localities that cannot be tracked to specific services. Nonetheless, comparisons of **Infant and Toddler Tracking System** data over time to determine statewide trends continue to be difficult due to ever-changing reporting requirements and formats. DBHDS has also expressed concerns about the reliability of the local data that it receives and, as a result, the ability to accurately determine funding allotments that localities should receive. Ongoing review of changes in expenditures for certain service categories, particularly since the implementation of the Medicaid Early Intervention Program, has also been affected.

Another recent positive development for the Part C system has been revision of **family cost participation practices** that help ensure statewide consistency and prevent denial of service due to inability to pay. Despite these changes, approximately 11 percent of children who are found to eligible do not access Part C services. Definitive reasons for this are not known but should be determined to ensure that children needing early interventions services receive them.

One recognized barrier to access of early intervention services appears to be persistent **lack of awareness regarding service availability**, particularly for underserved populations. An outreach campaign, “**The Earlier, the Better,**” was implemented by the Commonwealth a number of years ago, but out of necessity, funds for Child Find activities were diverted to direct services for children, and the lack of consistent outreach and public information efforts continues to deter early identification and front-loading of services.

In the early stages of life, hospital pediatricians, nurses, and discharge planners are critical sources of meaningful information for parents on available early intervention services, especially parents of infants receiving services in neonatal intensive care units (NICUs). Understandably, parents may not be able to receive or absorb much information while their child is in a NICU, and outreach efforts to them after the child been discharged can be invaluable in linking the child to early intervention services.

The Board recommends development and implementation of a formal follow-up program for families of children who have been in neonatal intensive care units, similar to the follow-up provided through the brain and spinal cord injury registry programs administered by the Virginia Department of Health.

In communicating with families, health providers must also be sensitive to cultural diversity and the ways in which culture affects delivery and access to services. As the Commonwealth’s population becomes ever more diverse, reaching families and children in meaningful ways becomes even more important in providing effective services. Information must be available in a timely manner and in understandable, accessible language and format. Health providers, as well as state agencies, must also plan communication with consideration for those who do not have access to a computer, which includes many of the elderly and the poor.

The 2010 *Report of the Virginia Health Reform Initiative Advisory Council*, produced at the direction of Governor Bob McDonnell, details the Commonwealth’s **continuing challenges in health care**. While not specific to individuals with disabilities, its key findings demonstrate how far Virginia has to go to develop a health care system that effectively serves all of its citizens. The report found that:

- “Nearly one million Virginians—and 150,000 children—lack health insurance and timely access to quality care that only it can ensure. Only 37 percent of small employers offer health insurance to their workers, a drop from 48 percent just ten years ago.

- “Virginia’s overall quality of care is average, with strengths in cardiac care, hospital care generally, and home health.
- “Health care spending is on an unsustainable path. Health care access, quality, and health status are inadequate for large numbers of Virginians.
- “By conventional measures of current workforce needs, demographic trends, retirement patterns and predicted replacement rates, Virginia is projected to soon have shortages of many health professionals on average, even without the impending coverage expansions expected from federal health reform. The scale of the projected coverage expansions will render all projected health professional supplies inadequate. We are therefore not likely to be able to provide care in the exact same ways we do now, for much longer.”

The report further noted that, although Virginia’s median family income ranks sixth among the states, it ranks 41st in breast cancer death rates and 35th in infant mortality rates despite improvements to newborn screening.

The 2006 and 2008 editions of the Board’s assessment addressed health care system issues as well. Most have not been mitigated and continue to be of concern, including:

- The lack of health insurance of over 1 million Virginians that limits access to health care for working citizens,
- The lack of dental care coverage under Medicaid for adults with disabilities,
- A shortage of health care providers willing and able to serve individuals with developmental and other disabilities,
- A lack of physical and operational accessibility and of reasonable accommodations in health care settings,
- Attitudinal and cultural barriers to health care access affecting both providers and individuals, and
- The need to improve coordination and continuity of care.

The health care system also remains fragmented and complex. Low provider reimbursement rates under Medicaid, as well as actual or threatened rate cuts due to the lingering effects of the recession on public revenues, pose challenges to the availability of affordable quality health care. Public comments to the Board indicate that access to health care providers who accept Medicaid (or Medicare) reimbursement is growing more difficult. Individuals who earn too much to afford private health insurance continue to fall through the cracks, and they are more likely to defer treatment until a health problem becomes severe, leading to more expensive interventions, including emergency room use.

The most significant recent development in national health care policy was the U.S. Congress’ passage of the *Patient Protection and Affordable Care Act* in 2010. Its long-term impact at the state level is uncertain at this time, since Virginia and many other states have filed

legal challenges to its implementation. Regardless of the outcomes of these challenges, it is clear that there must be significant changes with respect to access to, delivery of, and payment for health care, especially long-term care services for individuals with disabilities. The Commonwealth wisely made the decision to begin the implementation process and plan for key changes, such as electronic health records and health care exchanges, to improve the sustainability and effectiveness of the health care system.

As Virginia moves forward to improve its health care delivery system, keeping the needs of individuals with disabilities at the forefront of all discussions is paramount. Since service needs vary in scope and type by individual, a one-size-fits-all model will not be effective in achieving either desired health outcomes or cost control. Appropriate services and supports, including wellness care, delivered at the time and level needed, especially for infants and youth, will keep people healthier and more functional, avoiding more costly care.

As expenditures for public insurance programs such as Medicaid show, Virginians with disabilities, from infants and toddlers to the ever-growing elderly population, rely disproportionately on public services. The Virginia Department of Health (VDH) and its network of local health departments play a key role in providing access to these services. Local health department clinics are often the primary—or only—point of contact for access to services by low-income individuals and families. The regional Child Development Clinics provide comprehensive assessments that otherwise might not be available to youth. At this time, however, too little data is collected on utilization of public health clinics and related publicly funded programs by individuals with disabilities. For example, it is unknown how many individuals with disabilities receive dental care through medical school or health clinic programs.

To support planning by the Virginia Health Reform Initiative, **the Board recommends** that the state's Department of Health develop and implement a data collection system that will, where feasible, monitor the services provided to individuals with disabilities.

To ensure accessibility to health care for people with disabilities, increased outreach to the general medical community will also be required. The Commonwealth must improve expectations for training of all health professionals, beginning with the curricula at graduate and medical schools. Their students must be trained in person-centered practices, self-determination, and accessibility. Continuing education for current practitioners needs to be expanded to include these topics as well. To encourage more providers to serve individuals with disabilities, reimbursement rates for Medicaid must be restructured to establish parity with payments by private insurance plans. Additionally, those rates should be adequate to cover accessible equipment and other operational costs incurred in providing services for individuals with disabilities.

As in 2008, **the Board recommends** that incentives should be created or expanded to ensure that health professionals across the state establish and maintain inclusive and accessible practices.

Dental hygiene and preventative dental care have long been recognized as important to overall health and well-being for everyone. Regular dental care prevents plaque build-up and tooth decay that, if untreated, can develop over time into more serious, systemic infections or necessitate more expensive tooth extraction. Despite this, the state Medicaid program still does not cover routine dental services for adults, even though it does cover more expensive dental surgery and related procedures that might have been avoided through routine dental care. Moreover, Medicaid reimbursement rates for dental care remain below the costs for services, especially when specialized equipment, instruments, or staff with additional training may be needed and dental practices may experience higher liability insurance rates for employing them.

The Board recommends that:

- Dental coverage be added as a Medicaid State Plan service for adults,
- Medicaid reimbursement rates be increased to cover the true costs of dental services for all individuals, and
- The Department of Medical Assistance Services analyses of costs and benefits include examination and identification of the long-term cost avoidance that could be gained by providing preventive dental care for adults.

As indicated above, Medicaid is essential to receiving services and supports for many individuals with disabilities. In administering and ensuring fiscal accountability for this public insurance program, the Virginia Department of Medical Assistance Services (DMAS) has kept administrative overhead lean and implemented a number of best practices for quality assurance and cost effectiveness. For several years, DMAS has also conducted extensive outreach to families to expand Medicaid enrollment of children and youth. These outreach efforts, increased enrollment of individuals due to the economic downturn, and rising health care costs have made Medicaid the second largest expenditure in Virginia, and its expected continued growth is of concern to the state legislature. Nevertheless, as recognized by JLARC and legislative studies, Virginia's Medicaid reimbursement rates for Medicaid Home and Community Based Services (HCBS) Waivers are lower than those of other states and have not been adjusted for inflation.

The Board recommends that the Virginia Health Reform Initiative examine reimbursement rates for services under the Medicaid State Plan and for Medicaid Home and Community Based Services Waivers in comparison to private insurance rates and identify options to maintain or expand the pool of health care and related providers who serve individuals with disabilities.

During the past two sessions, the Virginia General Assembly has taken a number of **legislative actions addressing Medicaid HCBS Waivers and services** available through them. In the three years prior to the 2010 session, Medicaid data had shown a dramatic increase in the number of individuals enrolled in the Elderly or Disabled with Consumer Direction (EDCD) Waiver. The number of persons on waiting lists for the Intellectual Disability (ID) Waiver and Individual and Family Developmental Disability (DD) Waiver had grown significantly as well, and capacity was nearly reached for Day Support Waivers in state fiscal year (SFY) 2010. In response, the 2010 legislature directed DMAS and the Virginia Department of Behavioral Health and Developmental Services (DBHDS) to produce a plan with cost estimates for eliminating the ID and DD waiting lists by SFY 2020. Their analysis indicated that it would require funding of 1,100 new ID Waiver and 220 new DD Waiver slots per year for SFYs 2011 through 2020. Their study, however, did not examine the potential long-term savings that could be obtained through avoidance of expenditures for emergency care and institutional services.

Senate Bill 194, passed by the 2010 General Assembly and signed by the Governor, addressed an important Medicaid HCBS Waiver issue covered by a recommendation in the Board's 2008 assessment. As a result of this bill, individuals with disabilities receiving consumer-directed services under a Medicaid HCBS Waiver can obtain certain skilled services, such as insulin injections, without needing to have a nurse provider. Individuals with disabilities and their advocates fought hard for this change, an important reform with significant impact that will enable greater personal control over services that an individual would normally be able to self-administer if not for his or her disability.

The worsening effects of the recession on state revenues, however, also resulted in budget proposals during 2010 to reduce critical supports that would threaten the ability of individuals with significant physical or medical disabilities to remain at home. These included limitations on assistive technology and environmental modifications, reductions in respite care from 720 to 240 hours per year, and a cap of 40 hours per week on personal care services under the Medicaid HCBS Waivers.

Fortunately, the 2011 General Assembly passed several budget amendments that restored or lessened these cuts. Annual allowances for environmental modifications and assistive technology were maintained at \$5,000, rather than being reduced to \$3,000. Respite hours were partially restored to a maximum of 480 hours per year. Agency- and consumer-directed personal care hours under the Alzheimer's, EDCD, and HIV/AIDS Waivers were capped at 56 hours per week, for a total of 2,920 hours annually, but DMAS was directed to develop provisions for individual exceptions based on an individual's dependency in activities for daily living (ADLs), level of care, and risk of institutionalization. The cap does not affect services under the ID, DD, and Technology Assisted Waivers.

The 2011 legislature also approved funds for 275 new ID Waiver and 150 new DD Waiver slots. It further tasked DMAS and DBHDS with examining ways in which Medicaid HCBS Waivers could be improved or developed for individuals with intellectual or other developmental disabilities that would enable more people to be served in the community,

including those with high medical or behavioral needs, and would increase both efficiency and cost effectiveness (2011 Budget Item 295.1). Their report to the legislature is expected by October 1, 2011.

The Board applauds and supports this new Medicaid Home and Community Based Services Waiver initiative (2011 Budget Item 295.1) by the Virginia General Assembly to promote efficiency and effectiveness, and as in 2008, **the Board recommends:**

- Development of a “universal,” non-disability-specific waiver that offers a full menu of supports based on individual need;
- Analysis by the Department of Medical Assistance Services (DMAS) of future Medicaid costs and savings, including costs avoided for maintenance and upkeep of facilities by serving individuals in the community rather than in institutions;
- Collaboration by the Department of Behavioral Health and Developmental Services and DMAS to develop a waiver waiting list database that would include sufficient information on services actually needed to improve services planning and redesign; and
- Regular analyses of actual service utilization by DMAS that can be used to project needed capacity for various Medicaid services.

Many children, youth, and adults with disabilities require specialized services and supports in order to achieve independence and succeed in **education and employment**. As in many other areas of its assessment, the Board finds that most of the education and employment challenges cited in its 2006 and 2008 assessments remain.

A repeated key finding is that local control of Virginia’s public education system results in significant variability in the adequacy, level, and effectiveness of **educational services for children in grades kindergarten through 12**. While recognizing that local control is a core feature of the Commonwealth’s public education system, the Virginia Department of Education (VDOE) needs to continue efforts to improve accountability and achievement among localities. Disproportionate representation of minority students in special education is one concern, identified by both federal and state officials since 2005, that has been successfully addressed in recent years. Corrective action plans were developed and enforced, and this is no longer cited as an issue of noncompliance. Monitoring by VDOE, however, should be ongoing, even if it is not required by the federal government, to ensure that the Commonwealth serves its minority students with disabilities in an effective manner. Other areas of improvement since the Board’s 2008 assessment include:

- Closure of the underutilized and frequently criticized Virginia School for the Deaf, Blind, and Multi-Disabled in Hampton, allowing students to either be integrated into their local schools or to receive specialized services at the Virginia School for the Deaf and the Blind in Staunton;

- Fewer referrals to special education as a result of implementing a Response to Intervention (RTI) program at 15 pilot schools;
- Re-establishment of teacher preparation programs for teachers of individuals who are vision impaired at several universities; and
- A notable increase among students with disabilities in performance on standardized tests.

The good news noted in the last bulleted item above is tempered by the fact that standardized tests indicate a continuing disparity in achievement and graduation rates for students with disabilities, who have the lowest rate of obtaining a diploma within four years. Students with disabilities also score the lowest among all student subgroups, including students with limited English proficiency and those classified as economically disadvantaged. As a group, students with disabilities achieve a proficiency in mathematics and English that is eight to ten percentage points below established targets. A recent improvement has been participation by students with autism in VDOE's National Professional Development initiative, and results to-date, albeit limited, are positive.

The Board recommends that the Virginia Department of Education identify and continue to promote proven, evidence-based academic strategies that improve performance by and graduation rates for students with disabilities.

Federal special education laws mandate that students with disabilities be served in the "least restrictive environment." Despite this, with the notable exception of Montgomery County Public Schools, most school divisions across the state still have segregated self-contained classrooms, playgrounds or recreational activities, and even entire schools as a mainstay of their special education systems. Data shows that Virginia's targets for serving students in the least restrictive environment have not been met. Through due process and complaint filings, as well as public comment, parents continue to report a lack of qualified teaching staff, inaccessible schools and transportation, and a lack of support for inclusive educational practices. Increased and improved training for regular education and special education teachers is paramount.

The Board recommends that:

- The Virginia Department of Education provide increased technical assistance to school divisions to achieve least restrictive environment targets and implement enforcement actions when school divisions remain noncompliant over time, and
- College teacher education programs as well as continuing education for general education teachers include mandated components on collaborative learning, inclusive classrooms, diverse learning and instructional strategies, and behavioral supports.

Parents continue to comment on low expectations for their children by teaching staff, and of major long-term significance to their future, students with disabilities are too often directed

away from participation in the general Standards of Learning (SOL) curriculum and the standard or advanced diploma tracks. Families additionally voice confusion regarding the state's accountability process and that there are four different assessment tests from which to choose. Schools must ensure that students and their families understand the implications of curriculum and diploma choices on children's futures. Legislation passed in 2010 that requires documented justification when students are diverted away from the SOL assessment tests is a hopeful improvement.

The Board recommends that the Virginia Department of Education implement a monitoring process for local school system Standards of Learning diversion justifications in order to identify problem areas, provide technical assistance to localities, promote best practices, and enforce compliance.

Services for students with autism spectrum disorders (ASDs) continue to be a priority at the state and local levels as their numbers increase. The number of children identified as having an autism educational classification grew from 3,954 in 2003 to 10,092 in 2009, and when the 2010 Child Count is available in the spring of 2011, it is anticipated to be even higher. To better effect educational improvements, VDOE created an Office of Instructional Supports and Related Services in its Special Education Division. That office worked with JLARC on its 2009 *Assessment of Services for Virginians with Autism Spectrum Disorders*, which provides a blueprint for improving services for individuals with autism during all stages of life. Then, in 2010, VDOE established the Autism Center for Excellence in collaboration with Virginia Commonwealth University's School of Education and Rehabilitation Research and Training Center.

The Board supports the Joint Legislative Audit and Review Commission's 2009 recommendations for actions to improve autism services **and further recommends** that the Virginia Department of Education evaluate initiatives to improve educational services for youth with autism spectrum disorders to determine their impact on actual local practices and their effect on systemic change. This evaluation should be ongoing, and its findings should be published regularly.

Ongoing reductions in both state appropriations for local education agencies and local government funding are resulting in larger class sizes, reduced curriculum offerings, and less support for paraprofessionals in classrooms, all of which potentially contribute to widening of achievement gaps between students with and without disabilities. These budget cuts pose a major threat to meeting students' needs and further hamper inclusive school practices by depriving teachers of needed support.

The lack of **transition services** to life after high school is another ongoing concern for students with disabilities and their parents, whether those students will be graduating with their class or receiving education services through age 21. Although federal law assigns the primary

responsibility to provide transition services for students with disabilities to local school divisions, the participation of vocational rehabilitation agencies, Community Services Boards, and other state and local agencies is critical to successful transition to post-secondary options. Early in the transition process, which should begin no later than age 14 in Virginia, schools need to better coordinate with public and private agencies that are already working with a student or that can play a major role in preparing him or her for post-secondary education or employment.

Public comments to the Board continue to express dissatisfaction with the time at which the Department of Rehabilitative Services (DRS) becomes involved in the transition process for students as well as with the frequency and scope of the services that DRS provides for transition. This same concern has not been cited with respect to individuals accessing services from the Department for the Blind and Vision Impaired (DBVI), perhaps because DBVI provides “cradle to grave” services and these students and their families may already have connections with DBVI. The Board recognizes that DRS involvement may be hampered by a lack of timely referrals by schools; however, a new and very significant barrier is the recently announced “Order of Selection” limiting access to vocational rehabilitation services that DRS implemented effective March 1, 2011, which is discussed in more detail below. Whatever the difficulty, the Board believes that ensuring the best possible preparation for a child’s future should be a public priority.

The Board recommends that the Governor, through the respective Secretariats, charge the directors of the Department of Education, Department of Rehabilitative Services, Department for the Blind and Vision Impaired, and Department of Behavioral Health and Developmental Services to:

- Conduct a formal study of current processes and practices in transition services that will identify root causes of barriers to timely initiation of transition services and involvement of agencies in their planning and delivery, solutions to overcome those barriers and inefficiencies in the current system, and model transition processes and practices of other localities;
- Develop best practice guidelines for early interagency involvement in the transition process;
- Direct agency resources to ensure that coordinated transition planning and services occur at the local level; and
- Through improved data collection and analysis, monitor outcomes for students with disabilities over time.

Finding and maintaining employment for both students and adults with disabilities is a challenge complicated by a current employment services system that is fragmented and complex, with the Department of Rehabilitative Services (DRS), the Department for the Blind and Vision Impaired (DBVI), the schools, Workforce Centers, and various other agencies providing different employment-related services. The Board’s 2006 and 2008 assessments identified their

differing points of entry, application processes, and eligibility requirements as a considerable barrier to employment. Services currently available for individuals with disabilities, especially those with significant disabilities, are often inadequate, and expansion of vocational service capacity—a major overarching issue—requires development of not only job sites, but also individual training, placement, job coaching, and worksite accommodations such as assistive technology, workplace accessibility, and personal assistance services.

At the time of the Board’s assessment, budgetary issues further complicate access to employment and vocational services and supports for individuals with disabilities. Both DRS and DBVI were able to close previous Orders of Selection and serve more clients due to the infusion of federal “stimulus” funds provided through the *American Recovery and Reinvestment Act* (ARRA); however, those funds end in September 2011, and both agencies face fiscal challenges meeting the state match requirements for drawing down federal funds in the future. As a result, DRS reinstated its Order of Selection in March 2011, closing access to its vocational rehabilitation services for all categories of new applicants. Individuals may still apply for services, but those found to be eligible will be placed on a waiting list. DBVI is expected to reinstate its Order of Selection later in 2011. As noted above, students with disabilities are disproportionately affected by these Orders of Selection as new applicants seeking services to transition into advanced training, post-secondary education, or employment.

The Board recommends that:

- The Commonwealth provide sufficient state funding to eliminate vocational rehabilitation waiting lists for students ages 14 through 22, thereby drawing down additional federal funds; and
- The Joint Legislative Audit and Review Commission conduct a study of the effectiveness of current employment services for individuals with disabilities that will provide recommendations for system restructuring, as necessary, to improve individual employment outcomes.

Loss of benefits, especially eligibility for Medicaid, if their earnings are too high is a concern for many Virginians with disabilities seeking employment. The Virginia Health Reform Initiative report referenced earlier found that only 37 percent of all private employers in the state now offer health insurance. It also found that the cost of insurance premiums grows two to three percent faster per year than personal income and that some working Virginians need subsidies to afford the insurance needed to access appropriate care. As a result, many with a chronic health condition either do not seek employment or limit their hours of employment or wage levels.

MEDICAID WORKS, which addresses this issue, and other work incentives such as the Plan for Achieving Self-Support (PASS) and the Impairment-Related Work Expenses program exist, but many individuals with disabilities, their families, employment services professionals, and employers are not fully informed about them. Because eligibilities differ and regulations change periodically, ongoing outreach that brings up-to-date information to their target audiences

is essential to improve the utilization of these work incentives. An intensive training program sponsored by the Board, DRS, and the Department of Medical Assistance Services (DMAS) for state agencies, disability professionals, people with disabilities, and their families demonstrated this. Following the training, use of the 1619(b) work incentive allowing individuals to work while retaining Medicaid grew from 1,441 individuals in 2003 to 2,018 in 2007, a 40 percent increase. Based on this and other evidence, the Board believes that increased coordination among state agencies and federal Work Incentive Projects is indicated to better inform individuals about work incentives and encourage enrollment.

The Board recommends ongoing training and technical assistance about employment services and work incentives for staff members in state and local agencies serving 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.

Resources allocated for employment preparation are a valuable investment for the Commonwealth over the long-term. Employment services for individuals with disabilities can enable them to become more independent, productive employees and taxpayers that are less dependent on government services.

Virginia continues to operate many facility-based (sheltered workshop) employment programs that neither provide a competitive wage for individuals with disabilities nor help develop skills valuable to employers and constitute a form of segregation. This over-reliance on facility-based employment was noted in the Board's 2006 and 2008 assessments and was recently identified as an issue by the U.S. Department of Justice (DOJ) in its investigation finding that Virginia is in violation of the integration mandate of the *Americans with Disabilities Act* (ADA).

Other states have adopted an “**Employment First**” approach, in which training and education are provided to individuals with disabilities and their families, educators at all levels, state agencies, service providers, and employers not only to change expectations about the capabilities of individuals with disabilities, but also to promote regular employment versus day support or sheltered workshops as the first option for adult life. The State Employment Leadership Network (SELN), a statewide group of employment stakeholders that includes individuals with disabilities and is spearheaded DRS, is promoting an Employment First policy for Virginia, but a resolution calling for such a policy was defeated in the 2011 General Assembly. The SELN has also determined, and the Board concurs, that current Medicaid Home and Community Based Services (HCBS) Waiver reimbursement rules discourage individual, competitive employment placements.

The Board recommends that Virginia adopt an “Employment First” policy in which competitive, integrated employment is promoted as the first expectation for individuals with disabilities, and as a part of implementing this policy, **the Board further recommends:**

- Removal of the reimbursement rate differential that acts as a disincentive to competitive employment by increasing the individual supported employment rate so that it is greater than the facility-based employment rate and day support rate;
- Amending Medicaid Home and Community Based Services Waiver regulations, as recommended by the State Employment Leadership Network, so that individuals can access transportation via the Waiver for work purposes rather than have to be picked up at a waiver provider and dropped off at a waiver site; and
- Monitoring and data collection and analysis of outcomes for individuals with disabilities engaged in integrated, competitive employment to demonstrate the economic and social benefits over facility-based or day support programs.

As with employment services, the Board’s previous and current assessments have found the system of **community supports** to be fragmented and complex, requiring individuals with disabilities and their families to seek services from multiple state agencies and private nonprofit or for-profit entities. For the average citizen, just finding information on available state-funded or operated services can be challenging. Recent efforts to address this challenge, through the state’s “No Wrong Door” initiative, created the Virginia Easy Access online information resource. Although it was conceived as a one-stop source of information and referral for long-term care services, public comments and proposed 2011 legislative action indicate that it has not proved as user-friendly as anticipated and that it is underutilized. It is also limited to information on adult services and resources. To address some of these concerns, the Virginia Department for the Aging (VDA), which leads the No Wrong Door initiative, has been establishing local VirginiaNavigator Centers across the state as a walk-in resource for locating and completing applications for services. None of these initiatives, however, have had meaningful funding and a systemic plan by which to raise public awareness about their availability and promote their use statewide.

While it applauds state efforts to create and maintain a single source with which citizens can locate needed services, **the Board recommends** that:

- Current efforts towards that end across agencies be consolidated to prevent redundant efforts and create a true one-stop for information that includes resources relating to children with disabilities, and
- An outreach and marketing plan be developed and implemented through the Health and Human Resources Secretariat to inform citizens of the availability of these resources.

Assistive technology (AT) is an important tool that enables many individuals with disabilities to maintain independence, communications, or mobility. In recent years, with support from multiple grants, the Department of Rehabilitative Services (DRS) has worked to make AT more affordable and available through expansion of regional recycling centers that refurbish and adapt AT, as indicated, for reuse. In a related AT effort, the Woodrow Wilson Rehabilitation Center, operated by DRS, has actively promoted use of affordable electronic devices and other home technologies that assist individuals with disabilities in maintaining their independence.

In contrast with the recent expansion of regional AT recycling projects by DRS, financial pressures from the recession and slow economic recovery following it have severely constrained activities by other local elements of the service system as funding for key providers has been reduced. Lack of state funding has most severely impacted access to services by individuals with intellectual, developmental, and other disabilities who are uninsured or underinsured and do not qualify for Medicaid public insurance. These individuals often have no other option for services. For example, increased federal funding has expanded some services for former and current military personnel who have traumatic brain injuries, but state funds have not been allocated to expand services for other individuals with traumatic brain and spinal cord injuries.

Centers for Independent Living (CILs) are invaluable community resources for information and referral, peer counseling, training, and advocacy for individuals of all ages and with all types of disabilities. They support self-determination, independent living, and community integration by linking these individuals and their families to the services that enable persons with disabilities to remain in their homes and communities. They have also played a significant role in facilitating transition of individuals from institutional placements to community settings, first through the Board's nursing home outreach grant programs and then under the federal **Money Follows the Person** initiative. CILS still do not cover all localities across the state, and although some funding cuts were restored in Virginia's 2010 budget, additional funds are needed to establish CILS and provide their important services in unserved communities.

Local Community Services Boards (CSBs) administer a wide range of services for individuals with intellectual disabilities, both directly and through a network of private sources. CSBs, which receive state general funds, have historically been underfunded and experienced additional budget cuts in the three years prior to the Board's assessment. In 2009, Virginia finally created a state agency responsible for planning and coordination of developmental disability services, giving this responsibility to the Department of Behavioral Health and Developmental Services (DBHDS). The General Assembly did not allocate any funds, however, to expand developmental disability services at either the state or local level, and at present, most CSBs serve individuals with developmental disabilities only if they have a concurrent diagnosis of intellectual disability.

The Board recommends that the General Assembly prioritize expanded funding for disability services provided by public and private entities charged with service delivery to improve community capacity and to prevent institutionalization or re-institutionalization of individuals with disabilities, especially those who are uninsured or underinsured.

Adequate **system oversight** is essential to ensuring safety and quality of care for individuals with disabilities. For many years, staffing of licensure and related oversight functions at various disability agencies remained static despite dramatic increases in the number of community providers, programs, and service locations, then in state fiscal year (SFY) 2008, staffing was cut. This compromised the state's capacity to provide meaningful oversight over community- and facility-based programs. Legislative funding of additional licensure positions at DBHDS in 2011 was a promising sign; however, more positions are needed there and at other state oversight agencies. Better planning and implementation of oversight functions will be critically important as Virginia seeks to address the recent U.S. Department of Justice findings mentioned above and to transition individuals from institutional services to community supports.

In response to expanding community services for individuals with disabilities, **the Board recommends** that the Secretary of Health and Human Resources initiate a study of state agency oversight and quality assurance functions for community services that includes projections of staffing needs for the next six years.

When given the option, individuals with disabilities are no longer choosing to live in institutions, and as evidenced by the Money Follows the Person initiative, even individuals who were placed in institutions such as nursing homes many years ago want to have a home in their communities. The expectations of individuals with disabilities and their families have also evolved beyond artificial housing models, misnamed as "community integration," that feature large congregate group settings with little personal choice or control. They expect to have the same choices available to individuals without disabilities, such as apartment living with or without a roommate, home ownership, house sharing with friends or housemates of their own choosing, and living with family. These new expectations impact not only **community housing**, but the service system as a whole, reflecting an *à la carte* approach in which a "service package" based on a person's unique circumstances and choices can be individually designed. This growing emphasis on a community-based system of long-term care services is a national movement firmly grounded in law, public policy, and public opinion.

Although some changes are ahead, Virginia continues to have a public service system with an institutional bias. The Commonwealth funds and operates five **state training centers**, licensed as **intermediate care facilities for persons with mental retardation (ICFs-MR)**, for individuals with intellectual and related developmental disabilities (ID/DD). The state also has the tenth largest population among the states of individuals served in state institutions (approximately 1,100), and is one of ten states that have not closed any of their large state-operated ID/DD institutions. Nevertheless, as in other states, the training center census has been

declining and will continue to do so because of decreases in admission requests and increased demand for community options. Buildings at Virginia's training centers are at least 35 years old, with some being much older, and operational and maintenance costs for these structures and equipment have increased dramatically over time. Despite their on-going downsizing, these training centers will receive \$7.1 million in state fiscal year (SFY) 2012, an amount that will restore previous budget cuts and improve staffing ratios.

Moreover, between SFYs 2005 and 2010, the number of **community ICFs-MR** increased from 15 to 36 statewide, with a total capacity of 391 beds at the end of SFY 2010. Capacities ranged from four beds to 88 beds at the state's largest community ICF-MR, St. Mary's Home for Disabled Children, a specialized ICF-MR for children and adolescents in Norfolk, with most having eight or more beds. Youth ages one to 20 comprised 26.9 percent of community ICF-MR residents in SFY 2010, adults ages 21 to 64 comprised 68.8 percent, and 4.3 percent were ages 65 or older.

Far surpassing training centers and community ICFs-MR in number and capacity, 279 **nursing facilities (nursing homes)** operated in Virginia during SFY 2010. These facilities serve, and have served, individuals with developmental and other disabilities of all ages. Using the federal category of "blind and disabled" that includes those with ID/DD or acquired disabilities, the Department of Medical Assistance Services (DMAS) reports that 5,759 individuals were served in these facilities in SFY 2010, an increase of 14.1 percent over the 5,048 served in SFY 2007. While the state's training centers served only seven youth ages 21 or younger, community ICFs-MR served 105 youth, and nursing facilities served 89.

Resident counts specific to individuals with ID/DD served by nursing facilities in Virginia varies by source due to differing definitions of that population and differing data collection systems. Data from DMAS, based on information from the Uniform Assessment Instruments (UAI) that it receives, show that 906 individuals with ID/DD were served in nursing facilities in SFY 2010. That is an undercount, since DMAS has received UAI on only 64.4 percent of all those served under Medicaid. In contrast, the Coleman Institute at the University of Colorado reports data collected from both state ID/DD agencies and from the federal Centers for Medicare and Medicaid (CMS) Online Survey, Certification, and Reporting (OSCAR) system. Its most recent national report indicated the count as being 1,184 in SFY 2009. The University of Minnesota reports an even higher count of 2,877 in SFY 2009.

Both ICFs-MR and nursing facilities rely on public insurance for funding, primarily Medicaid and to a lesser extent Medicare, and concerns about the sustainability of Medicaid must take into account the role and costs of serving individuals with ID/DD in institutions. In SFY 2010, the annual per capita cost of providing services in a training center was \$195,574, compared to \$137,552 in a community ICF-MR. The *Genworth 2010 Cost of Care Survey* indicated that the 2010 median per capita cost for services in a Virginia nursing facility ranged from \$65,700 to \$73,000.

The state's institutional bias is contrary to the clear choices made by individuals with ID/DD and their families to live in and be part of their communities. The U.S. Department of Justice's February 2011 notice of findings points out that segregation in institutions both harms individuals, through such effects as learned helplessness and a lack of or loss of skill development, and is contrary to the *Americans with Disabilities Act* (ADA). The state Inspector General for Behavioral Health and Developmental Services also determined that those in Virginia's training centers could be served in the community.

Steps taken in other states show that planning for downsizing or potential closure of the state's training centers must be concurrent with planning for development of appropriate community infrastructure and oversight systems. Research also indicates that, while they initially rise during this process, total Medicaid costs decline after several years. Virginia stands to benefit fiscally in other ways as well. When an institution closes, substantial costs for building maintenance will be avoided. Surplus land can be sold and revenues from those sales applied to support community services, expanding jobs related to disability services beyond just those localities where institutions are currently situated to all communities. The 2011 General Assembly took a meaningful step in this direction by supporting the Governor's proposed \$30 million "down-payment" to build community service capacity for persons with ID/DD with the appropriation of that amount to create a **Trust Fund for Behavioral Health and Developmental Services**.

The Board recommends that state and local policymakers, in coordination with individuals with disabilities, advocates, service providers, and other stakeholders, fully analyze the design and operation of the state and local services system for individuals with intellectual and developmental disabilities. This analysis should then be used to develop workable, sustainable changes, with specific implementation timelines and resource requirements, that will expand disability services at all levels consistent with the tenets of community inclusion and integration as well as individualized supports based on need, not diagnosis or program availability. While some efforts in this direction are already underway, greater attention is needed to system elements that support institutional services over community supports.

The Department of Behavioral Health and Developmental Services' (DBHDS) development of and continued efforts on its *Creating Opportunities* plan are a good start, and the agency is commended for its inclusion of diverse stakeholders. As these efforts continue and expand, however, the Board cautions that planning must be careful to prevent "trans-institutionalization," the movement of individuals with ID/DD from one type of institution, such as the training centers, to another type of institution, such as community ICFs-MR or nursing facilities. Census trends at institutions for all populations, but especially for youth and young adults, also merit ongoing scrutiny. Factors leading to institutional placements should be

identified and addressed. The need to do so will become increasingly more important because of federal requirements that nursing facilities determine whether individuals are interested in and prefer community supports as a part of their annual service planning process.

Tracking these activities are complicated by the **lack of reliable, valid data** on the number and characteristics of individuals with ID/DD served in community ICFs-MR and especially in nursing facilities. As referenced above, in preparing its assessment, the Board found that nursing facility residency counts varied dramatically depending on which agency database and methodology was used. This problem has been substantiated by researchers at the University of Minnesota and University of Colorado, which each produce annual national reports on residential services for individuals with ID/DD. For Virginia's Health Reform Initiative to develop effective long-range plans, it is vital that it have access to accurate and consistently determined information addressing these and other issues affecting services for individuals with disabilities.

The Board recommends that the Secretary of Health and Human Resources:

- Task the Department of Health, Department of Medical Assistance Services, and Department of Behavioral Health and Developmental Services with developing a common methodology, including diagnostic categories, for identifying and tracking individuals who are served in non-state-operated institutions by age and by whether they have an intellectual or other developmental disability;
- Establish a lead agency for monitoring and reporting annual data trends; and
- Incorporate this data into planning as a part of the Virginia Health Reform Initiative.

Affordable, accessible housing is critical to successful community integration, and the U.S. Department of Justice's (DOJ) Office of Civil Rights is increasingly holding states more accountable for enforcement of the community integration mandate under the *Americans with Disabilities Act* (ADA) and the U.S. Supreme Court's *Olmstead v. L.C.* decision. In support of greater community integration, recent federal initiatives have been and are providing incentives for states committed to related changes in policy, systems design and funding models. These include the Money Follows the Person demonstration project funded by the Centers for Medicare and Medicaid Services (CMS), passage of the *Frank Melvin Supportive Housing Act* by the 111th U.S. Congress, and the U.S. Department of Housing and Urban Development's (HUD) *Notice of Funding Availability for Housing Choice Vouchers* targeting nonelderly people with disabilities. There will be additional opportunities for states to obtain federal funding and technical assistance through similar grants and demonstration projects promoting systems change, and Virginia needs to proactively position itself to capitalize on these opportunities.

At the time of the Board's assessment, the Commonwealth still lacks a **comprehensive housing policy**; however, the *Governor's Executive Order No. 10*, issued in April 2010, calls for establishment of a *Housing Policy Framework* that will align priorities, goals, and resources strategically in a coordinated manner. On November 18, 2010, the workgroup fulfilling this executive order submitted an interim report to the Governor that stressed the importance of addressing the lack of community housing options for people with disabilities. Noting the *Olmstead* mandate for state community integration strategies, the report concluded that Virginia has a "...growing need to reduce institutionalization and provide more integrated community housing alternatives for special need populations." It also highlighted the common barriers to community housing for individuals with disabilities: affordability, accessibility, and coordination of services.

With respect to affordability, people with disabilities who rely on Supplemental Security Income (SSI) benefits as their only income continue to be some of the poorest Virginians, able to afford a monthly rent of no more than \$191 per month (30 percent of the \$674 monthly SSI benefit at the time of the Board's assessment). In the 2009 *Appropriation Act* (Budget Item 315 Z), the General Assembly called for a study that would "...report on investment models and best-practices for the development of affordable and accessible community-based housing for persons with intellectual and related developmental disabilities." The Department of Behavioral Health and Developmental Services (DBHDS) was given responsibility for leading this study in collaboration with the Virginia Housing Development Authority, the Department of Housing and Community Development, the Virginia Association of Community Services Boards, The Arc of Virginia, and the Virginia Network of Private Providers. Although the Board was not a mandated participant, it was a key contributor to the study's comprehensive overview of affordable housing barriers, current resources, and opportunities and to its specific recommendations for implementing expanded housing options.

To-date, attempts to establish a Housing Trust Fund for Virginia have also been unsuccessful, and as the state explores resource reallocations and other changes needed to rebalance its long-term care system, increased efforts are needed to obtain a commitment of resources for integrated housing options and choices. The *National Affordable Housing Trust Fund Act* of 2008 dedicates funding for the production, preservation, and rehabilitation of 1.5 million affordable homes over ten years. At least 67.5 percent of the funds it provides to states must be spent on rental housing for households with incomes at or below 30 percent of state median income. Virginia is expected to receive approximately \$19 million in federal funds through this legislation, but their release date has not been confirmed.

A significant contributing factor to the shortage of accessible housing is the lack of awareness of the *Fair Housing Act*, the *Americans with Disabilities Act* (ADA), and the general principles of "universal design" and accessibility among builders, inspectors, landlords, and realtors. For the fourth consecutive year, HUD's 2009 *Annual Report on Fair Housing* identified

disability as the most common basis for housing discrimination complaints filed with fair housing and equal opportunity agencies. Resistance to the development of housing options for people with disabilities exists in some localities as well, largely due to misconceptions and inaccurate stereotypes. Available data further supports the need for increased outreach and education to raise awareness and understanding among key local stakeholders.

To expand the availability of affordable, accessible housing options, **the Board recommends** that:

- Cross-Secretariat collaboration be sustained to implement the housing policy recommendations and next steps identified in the *Report on Investment Models and Best Practices for the Development of Affordable and Accessible Community Housing for Persons with Intellectual and Related Developmental Disabilities* (2009 Budget Item 315 Z);
- The Commonwealth develop a mechanism to overcome critical funding gaps limiting development of affordable housing for people with disabilities through targeted application of state funds that make investments of private capital more feasible;
- Virginia make the housing needs of people with disabilities a priority and ensure that fair housing laws and policies are upheld and enforced in planning for and dispersal of its National Affordable Housing Trust Fund allocation; and
- Compliance with the *Fair Housing Act* be rigorously enforced and that statewide outreach and education strategies to inform builders, developers, realtors, housing counselors, elected officials, and community organizations about the law be developed and implemented.

Coordinated local planning for housing, transportation, employment, and other land uses is critical if tangible improvements in community living opportunities are to be realized, and of these, **transportation issues** continue to be one of the most frequently cited barriers to full community inclusion for people with disabilities. Reliable transportation is essential to maintain employment, receive medical other health care services, shop for groceries and other personal needs, and participate in recreational or civic activities. To address these issues, the Department of Rail and Public Transportation (DRPT) has worked closely with localities to develop Coordinated Human Services Public Transportation Planning Models. While significant gains have been achieved in these efforts, continued planning and implementation of coordination strategies are needed.

Many individuals with and without disabilities rely on dependable public transportation for their basic mobility, and the current strain on local fiscal resources is making it increasingly difficult for localities to provide stable, adequate annual appropriations for public transportation.

Localities also lack resources to make investments in sidewalks and curb cuts that create unobstructed pedestrian routes and ease travel through neighborhoods to public transportation and other destinations. Opportunities exist to access federal resources supporting local transportation coordination efforts, but many localities have been inconsistent in planning for the matching funds required to obtain those federal funds.

The true cost of transportation services by many human services is also difficult to determine because they are not tracked by trip and passenger, making it difficult for policymakers to compare costs per unit of service. Human services agencies also frequently do not account for all costs associated with providing transportation, such as vehicle maintenance and upkeep, related office space and equipment, and comprehensive accounting of staff costs. Because providers do not use uniform methods of data collection, a universal method of evaluating the success of a particular location's transportation coordination efforts is not available.

Virginians with disabilities continue to express complaints and concerns to the Board about the quality of both paratransit services and Medicaid-funded human services transportation, as well. An apparent lack of driver training and sensitivity to the diversity of disability populations and their needs and the lack of reliability are identified most often. While the full scope of the problem is not clear, individuals with disabilities report that, when drivers are late or just do not appear, they are often "penalized" for late arrivals or missed appointments by health care providers through additional charges or even discontinued services if it occurs repeatedly. Data maintained by the Department of Medical Assistance Services for human services transportation indicates that a sizeable proportion of complaints are for transport that is late or does not show, but it also indicates that fewer than one percent of all rides result in complaints.

To increase the availability and reliability of transportation for individuals with disabilities statewide, **the Board recommends** that the Commonwealth:

- Continue to emphasize development of coordinated planning models in local and regional planning and develop incentives that facilitate community development linking housing, transportation, and disability services;
- Encourage localities to include funding for public transportation as a line item in their budgets;
- Consider creating incentives for localities which designate matching funds for federal transportation dollars on a sustainable, long-term basis;
- Develop and implement a competency-based driver training curriculum for all human services transportation and public paratransit drivers that includes not only driver

safety, but also training on diverse disabilities, disability culture, and disability etiquette;

- Conduct regular monitoring of trends regarding complaints received by the Medicaid Transportation Advisory Council (MTAC) that transportation is late or does not show, which considers the impact of this problem on individuals with disabilities;
- Encourage local governments to include capital investments for accessibility enhancements and “universal design” features that remove travel barriers to individuals with disabilities in their annual budgets; and
- Require the Department of Rail and Public Transportation to make recommendations and supply technical assistance to service providers and localities regarding model transportation coordination methods and to develop and implement a standardized data collection system that can be used to determine the true cost of providing transportation services and measure the success of transportation coordination efforts.

With significantly more individuals with disabilities living in the community, their protection and support in the event of a disaster or other emergency is of growing importance, and **emergency preparedness and response planning** by the state and local governments has made progress since the Board’s 2008 assessment. Emphasizing individual preparedness, the Virginia Department of Emergency Management (VDEM) has taken steps to better prepare individuals with disabilities to shelter in place, providing related information to state disability agencies and making it available on their website. VDEM has also developed a uniform emergency preparedness template for use by localities to ensure that the needs of individuals are addressed in emergency preparation and planning activities. In developing the Commonwealth’s *Emergency Operations Plan* and in other planning activities, VDEM included disability services agencies as partners and formalized the roles and responsibilities of local and state disability services agencies in emergencies. The number of state-managed shelters across the state has expanded, and emergency exercises have included evaluators from disability services agencies.

The Department of Behavioral Health and Developmental Services (DBHDS) and the Department of Social Services (DSS) have revised their regulations to clarify the responsibilities of facilities and programs that they license in local emergency and evacuation planning, response, and evaluation. At this time, however, statewide monitoring and evaluation of these plans by those regulatory authorities to determine whether best practices have been adopted and identify deficiencies remain limited. The Board’s 2011 assessment further notes that significant improvements remain to be made by all state, regional, and local agencies responsible for responding to emergencies. Dissemination of information about the local availability of accessible shelters and accessible transportation in place for emergencies is especially lacking. The extent to which individuals with disabilities and their families are being involved in regional and local emergency planning and training activities is also not known.

In conclusion, the summary above and the more detailed information contained in the chapters on individual services of the 2011 *Assessment of the Disability Services System in Virginia* fulfill the Virginia Board for People with Disabilities' state and federal mandates as the Commonwealth's Developmental Disabilities Planning Council to provide a description of the disability services available statewide that are funded, operated, or licensed by the state. Development of this report would not have been possible without the extensive information and review provided by multiple state agencies. After review of this information and consideration of input provided by diverse stakeholders across the state, in keeping with its federally mandated role, the Board drafted the key findings and recommendations above to promote systems change, increase service capacity, and promote community integration for Virginians with disabilities.

Through these assessment recommendations, **the Board advocates for expansion and, in some cases, redesign of all disability services**, including those provided by contract, so that:

- ✓ Individuals with disabilities have access to and receive flexible, person-centered services and supports as needed for their lifespans;
- ✓ Supports are *front-loaded* to provide services as soon as indicated at appropriate levels;
- ✓ Individuals are served in inclusive, integrated community settings;
- ✓ Accountability exists for service quality and effectiveness that includes transparency through publication of agency and program funding, expectations, and actual outcomes;
- ✓ Meaningful, consistent oversight is provided to ensure service quality, timeliness, and appropriate outcomes; and
- ✓ State disability agencies have both the capacity and a mandate for identifying, collecting, analyzing, and publishing meaningful outcome data regarding programs or services.

State leadership can significantly transform services for Virginians with developmental and other disabilities by ensuring that these features exist in developing or expanding services.