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Volume 1: Key Findings and Recommendations

A companion to the complete 2014 Assessment of Disability Services in Virginia

I. Executive Summary

About one in five Virginians have some type of disability, either permanent or temporary. Over 127,000 Virginians have a developmental disability (DD). In passing the federal Developmental Disabilities Bill of Rights Act (DD Act), most recently authorized in 2000, Congress found that

disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society.

The Virginia Board for People with Disabilities (the Board) serves as Virginia's Developmental Disabilities Council, authorized and principally funded under the DD Act. The Board, through its state (Virginians with Disabilities Act) and federal authorization has a responsibility to influence and guide the policies and practices that govern the delivery of services and supports to persons with developmental and other disabilities living in Virginia.

In 2009, the Board developed its *Benchmarks for Evaluating Public Policy in Virginia*. These benchmarks continue to guide the Board's work. They provided a framework for the agency input, public comment, and data gathered and analyzed in the course of this assessment and are the basis for many of the Board's recommendations. The benchmarks supply policymakers and providers with a critical checklist for decision-making:

- ✓ **Front-loaded supports.** Publicly funded supports to children and adults with disabilities and their families are "front-loaded" (provided as soon as indicated) at levels designed to reduce services needed over the individual's lifespan and to maximize opportunities to give back.
- ✓ **Inclusive settings.** Individuals with disabilities receive services and supports appropriate to their needs in inclusive community settings. They are not segregated from their fellow citizens.

- ✓ **Person centered.** 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.

The Virginia Board for People with Disabilities makes the benchmarks available for download in various forms for printing, including a mailable brochure, through its website at <http://vaboard.org/vapolicy.htm#benchmarks>.

A. Scope and Organization

The *2014 Assessment of Disability Services in Virginia* examines and describes the status of services provided at a point in time. While the focus is on services and supports for individuals with **intellectual and developmental disabilities (ID/DD)**, many of the areas covered—such as housing, transportation, education, and employment—are relevant to all disability populations. The *2014 Assessment* examines how (or whether) services have changed since the 2011 edition of the Board's *Assessment*.

Unlike previous editions, the *2014 Assessment* is provided in two companion volumes. The *Key Findings and Recommendations* presented here constitute **Volume 1**. The Board's comprehensive description and examination of disability services in Virginia constitute **Volume 2**. Individual chapters in *Volume 2* provide the scope of the *Assessment* as well as the context and data used to develop these findings and recommendations. Following the **Systemic Recommendations** presented below is a **Quick Reference List of Recommendations**. These recommendations are presented with the full context of the Board's findings in the **Key Findings and Recommendations** section of this volume.

The nine chapters in *Volume 2* provide the Board's full assessment of disability services, addressing the major service areas of: early intervention, education, employment, health care, Medicaid, institutional supports, community living supports, community housing, and transportation. They include information on Administration and General Assembly actions to improve the quality, effectiveness, and delivery of services since 2010 (described in the *2011 Assessment*). The chapters additionally describe the specific services provided and identify service gaps, the complexities of service access, utilization, and delivery as well as their funding

sources, performance, and barriers to improvement. A comprehensive reference list concludes each chapter. While the service descriptions are a snapshot at a point-in-time—primarily the end of state fiscal year (SFY) 2013—longitudinal trend data is provided whenever available. In addition, data and information from SFY 2014 have been incorporated where available.

This document serves as a resource to promote additional policy discussions on the design and delivery of disability services from a systemic perspective. It also offers recommendations designed to move the services system forward.

Since 2010, numerous changes in programs and services have occurred. With these reforms comes an important opportunity to ensure that the Commonwealth continues to move forward, to examine and evaluate how well we serve our citizens with developmental and other disabilities, and to create a more flexible, efficient, responsive, and cost-effective service system.

B. Context for Recommendations for Reform

Despite the high average per capita income touted for Virginia, there is considerable income inequity within regions of the State. Virginia has many pockets of poverty at local and regional levels. Those same areas historically have had the most **difficulty attracting service providers** as well as employers. In addition, many Virginians with disabilities are reliant on Medicaid. As noted by the 2012 Joint Legislative and Audit and Review Commission (JLARC) study (*Senate Document #8, 2013*), Virginia's **Medicaid reimbursement rates** have been relatively stable over the past decade, while payment rates by private insurers increased along with care costs. Due to its stringent financial eligibility criteria, many low-income adults do not have insurance and rely on the limited number of "safety net" of providers or even hospital emergency rooms for health care.

The annual report, *State of the States in Developmental Disabilities*, provides extensive comparative state data on services and supports provided to individuals with ID/DD. Based on data for 2011 on individuals with ID/DD residing in out-of-home settings, the report ranked Virginia as 40th in the number of individuals residing in out-of-home settings with 1 to 6 beds. (The out-of-home settings included state-operated Training Centers, nursing facilities, non-state-operated intermediate care facilities for individuals with intellectual disabilities (ICFs/IID), and congregate group homes [Braddock et al., 2013]). In addition, Virginia ranked 12th in the number of individuals with ID/DD residing in large (16 beds or more) institutional settings; and those in large settings comprised 26 percent of all Virginians with ID/DD living in out-of-home settings. Although the census at its state-operated Training Centers has decreased significantly over the last 4 years, Virginia continues to lag behind other states when it comes to providing residents with appropriate, community-based **alternatives to institutions**.

Virginia also ranks poorly in terms of how it stacks up against other states with respect to **inclusion** of individuals with disabilities. The Case for Inclusion 2014, the latest annual report

from United Cerebral Palsy (UCP), ranks the states and the District of Columbia regarding Medicaid-funded services and supports for individuals with ID/DD. State rankings focus on four major person-centered outcome domains:

- live in and participate in their communities;
- live satisfying lives and have valued social roles;
- have sufficient access to and control over needed support so that the assistance they receive contributes to lifestyles they desire; and
- are safe and healthy in the environments in which they live.

In the 2014 report's overall ranking, which considers the degree to which each state achieves all of the above outcomes, **Virginia ranked 49th**. The Commonwealth ranked 48th in promoting independence and in reaching those in need, but had significantly higher rankings in certain outcome domains: 20th in tracking health, safety, and quality of life; 27th in keeping families together; and 17th in promoting productivity. All of these areas require increased efforts to support individuals with disabilities across the lifespan.

Since the Board's last *Assessment*, numerous external forces have been reshaping or influencing the means, scope, and delivery of disability and related health care and services. The most significant factors for Virginia are

- the slow and uneven economic recovery;
- implementation of the federal Affordable Care Act and other health care reforms;
- changes in federal Medicaid regulations regarding community services/supports;
- state and federal budget decisions (and indecision), especially regarding the Medicaid program;
- demographic trends, especially growth in the number of citizens who are elderly as "baby boomers" age and the increased longevity of individuals with disabilities, including those with complex medical needs; and
- the Commonwealth's 2012 Settlement Agreement with the US Department of Justice.

Of these, the most immediate impact on disability service design for individuals with intellectual and developmental disabilities (ID/DD) resulted from the Virginia's **Settlement Agreement with the US Department of Justice**. Between 2008 and 2010, the US Department of Justice (DOJ) investigated the services provided to Virginians with ID or DD in both state Training Centers and in communities; it issued its findings in 2011. The final, court-approved agreement was signed in August of 2012. Findings, reports, and other documents related to the Settlement Agreement are discussed in greater detail in *Volume 2* of this Assessment and can be found at <http://www.dbhds.virginia.gov/Settlement.htm>.

Through the DOJ Settlement Agreement, the Commonwealth made a 10-year commitment to numerous actions that would ensure that **individuals with ID/DD live quality lives in communities**, not in institutions. These actions include developing and/or expanding appropriate community-based services and supports to meet the needs of these individuals and their families. The target populations covered under the Agreement include individuals with ID or DD in state-operated (Training Centers) and non-state-operated ICFs/IID or in private nursing facilities. It also includes all individuals who are living in their communities and are eligible for or receiving services under a Medicaid Home and Community Based Services (HCBS) ID, DD, or Day Support Waiver, including those on wait lists for an ID or DD Waiver.

To accomplish the Agreement requirements, Virginia's leadership determined that (1) operating a dual system of disability services (delivered in large institutions and in community settings) is neither feasible nor sustainable over time, either programmatically or fiscally, and (2) the overwhelming majority of individuals with ID/DD and their families want to be served in and to participate in their communities. Virginia's commitment includes but is not limited to:

- significant expansion of community-based housing,
- employment and integrated day activities for individuals with ID/DD,
- improved system and service oversight and quality assurance, and
- the transition of individuals with ID/DD from state- and non-state-operated institutions into the community, including the closure of four of its five state-operated institutions (Training Centers) by 2020.

The Commonwealth will experience significant growing pains as it develops a more robust community-based system of services and supports for people with ID/DD. Managing the multiple priorities of growth while ensuring quality will bring significant challenges. Such change requires strong, consistent leadership with the support of policymakers and administrations that change over time. Attention must be paid to the infrastructure, staff composition, and training and resources for the agencies and providers who support individuals with ID/DD.

Access to quality **health care** is an essential component of a strong service system. Many individuals, particularly those with significant disabilities, are reliant on Medicaid for their health care. Over the next decade, additional factors are expected to contribute to increases in both Medicaid enrollment and health care costs, including rising medical costs, the growing elderly "boomer" population, implementation of the Affordable Care Act, federal budget decisions, and state initiatives to expand and improve access to publicly funded health care and long-term care supports in the community.

When considering Medicaid cost, however, the Commonwealth must also consider the potential for **cost avoidance**. For individuals who are elderly or who have a lifelong disability, Medicaid can enable them to receive services that not only help maintain their functional

abilities and self-sufficiency but also avoid more expensive services and care, including institutional care. Medicaid-funded services for children can prevent institutionalization, ameliorate medical conditions, and provide critical therapies that enable them to reach critical developmental and other milestones.

As the Board's *Benchmarks for Evaluating Public Policy in Virginia* state, services and supports must begin as early as possible for those in need. Evidence is clear that infants and toddlers with disabilities who receive services and supports at adequate levels have better outcomes than children who don't receive services early in life. **Early intervention** can reduce functional impairments later in life, thereby promoting more self-sufficiency. 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 infants and child age. Since 2011, the date of the Board's last *Assessment*, Virginia has experienced some improvements and also some setbacks that are discussed in the section below.

Likewise, there have been numerous changes in K–12 education affecting students with and without disabilities. There are some positive findings to report. However, there also remain numerous challenges for students with disabilities and their families seeking to ensure receipt of a free and appropriate public education (FAPE) as guaranteed under the federal Individuals with Disabilities Education Improvement Act (IDEA). Outcomes for students with disabilities in terms of obtaining employment or proceeding to post-secondary education following high school are poor; much work is needed to ensure that Virginia's children receive an **education** that enables them to be successful in adulthood.

The challenges of finding and maintaining **employment** affect both students and adults with disabilities. The current employment service system is fragmented and complex, with various state and local agencies providing different employment-related services. As reported in previous editions of the *Assessment*, this fragmentation presents a considerable barrier to employment. Virginia has taken an important first step by establishing an *Employment First* policy; however, it now needs to move more aggressively to implement that policy. More effort and coordination is needed to ensure equal economic opportunity for individuals with disabilities.

The foundation of inclusive communities and active participation in those communities is access to education, employment, social relationships, and safe, affordable, and accessible housing. To create real and meaningful opportunities for individuals with disabilities to live inclusively in communities, it is necessary to acknowledge the **community housing challenges** associated with the deep poverty that affects the majority of people with disabilities. In Virginia and nationally, individuals with disabilities receiving Supplemental Security Income (SSI) benefits or whose income is otherwise limited continue to be priced out of the housing market. Affordability is at the core of providing meaningful opportunity for accessible community housing for individuals with disabilities.

There have been numerous studies over the course of many years on how to expand housing opportunities for individuals with disabilities, including individuals with ID/DD, many of whom would prefer to live in more integrated, independent housing. The Settlement Agreement with the US Department of Justice required development of a Housing Plan that—if fully implemented and resourced—will help ensure that individuals with ID/DD have real choices.

Transportation issues are also among the most frequently cited barriers to full community inclusion. Reliable transportation is essential to maintain employment, receive medical and health care services, do grocery shopping, and participate in recreational or civic activities. The current strain on local fiscal resources is making it increasingly difficult for localities to provide stable, adequate annual appropriations for public transportation. Individuals with disabilities, like all public transit users, require transportation that is dependable over time for their basic mobility.

In this volume, the Board identifies its key findings from the available information and puts forth recommendations to improve services and supports for individuals with developmental and other disabilities. The Board offers both recommendations for systemic change as well as targeted recommendations regarding specific service areas. Readers are encouraged to review the full *2014 Assessment* provided in *Volume 2* or to review individual chapters of interest for significant additional data and findings (<http://www.vaboard.org/assessment.htm>).

C. Systemic Recommendations

Disability services are currently delivered through a fragmented set of systems developed around service areas and agencies. To fulfill its commitments to the DOJ Settlement Agreement, to state and federal laws pertaining to services for people with disabilities, and to taxpayers, Virginia needs a single, person-centered disability services system with **integrated, long-range planning and consistent oversight**. The Board offers the following recommendations to improve disability service access, availability, quality, and oversight across state agencies. The Board believes that state **agency accountability for service quality and effectiveness** should be a top priority not only to ensure individual outcomes, health, and safety but also to ensure appropriate stewardship of taxpayer funds. A commitment to meaningful, consistent oversight and valid data is, therefore, required.

The Board recommends that **the Commonwealth**:

1. Mandate and provide funding for state disability and other related agencies to (a) identify, collect, analyze, and provide **valid utilization and outcome data** for each program or service category and (b) develop/maintain substantive quality assurance processes for monitoring service or **program effectiveness**.
2. Require state agencies to improve and update **website information** at least annually to ensure transparency for Virginia's citizens. Major initiatives, core activities, and program

outcomes (positive or negative), as well as changes in service availability and to service models should be available online and presented in user-friendly, easy-to-find web pages.

3. Examine **funding trends** for services to Virginians with disabilities provided by Health and Human Resource (HHR) agencies. The limited information and data that the Board was able to obtain indicates an alarming reliance on federal funding along with low state funding (less than 25 percent in some instances). Any significant budget decrease by Congress is likely to have major impacts on the provision and availability of services not only for Virginians with disabilities but also those without who are poor and uninsured.

Numerous factors have contributed to a rapidly changing environment for health care and related disability services. Given these significant environmental changes, now is the time for the Commonwealth to examine and evaluate how well current disability services are delivered and working to create a more flexible, efficient, responsive and cost-effective service system.

The Board recommends that the **Secretary of Health and Human Resources (HHR)**:

4. Engage agency leaders to develop a **10-year plan** for transforming state administered and funded services for Virginians with intellectual and developmental disabilities (ID/DD) into an efficient, effective, and accessible system of care. Development of this long-range plan should consider the following issues.
 - a. What should the **future roles** be for each agency? Is the current organization of agencies within the HHR Secretariat adequate to meet the growing challenges of the evolving environment?
 - b. How has the level of **state funding** for disability services changed over time? What impacts do federal funding or mandates have on the scope and type of services delivered? What is the potential impact of future potential cuts in federal funds for disability services?
 - c. What **processes** should be in place to improve (i) care coordination and timely, appropriate levels of services across the lifespan and (ii) interagency collaboration to resolve long-standing service gaps and problems?
 - d. How can desired **outcomes** be best achieved? How can oversight of the quality of services be strengthened? What staff talent, capacity, and infrastructure are needed by state disability agencies to do so?
 - e. How effective are state agency **outreach** tools in helping individuals locate and understand available services?

The resulting **blueprint** should be used to improve fiscal and programmatic outcomes for disability services provided through agencies of the HHR Secretariat. As a more immediate action, and as part of strategic and other planning efforts, the Board recommends that **the Commonwealth**:

5. Require HHR agencies to work in collaboration to **identify potential impacts of any significant changes** in its service models or scope of services on its programs and determine how to eliminate silos in program and service planning, development, and implementation.

D. Quick Reference List of Recommendations

The Board's recommendations are provided here in list form without commentary for quick reference. To read the recommendations with the benefit of the full context of the Board's findings, see the section of this volume.

Early Intervention

To provide **front-loaded supports** that maximize positive outcomes for infants and toddlers and offer the highest potential for long-range cost avoidance, Virginia's Early Intervention (EI) Services must be delivered at the earliest juncture possible. The Board recommends that the **General Assembly**:

1. **Fully fund the Part C Early Intervention System** to ensure that children are evaluated as soon as possible and have access to the level and intensity of services and supports needed as soon as eligibility is determined.

The Board further recommends that the Commonwealth, under the leadership of the **Health and Human Resources Secretariat**:

2. Improve accountability by developing and implementing **a statewide data system** that eliminates inconsistencies in local reporting, eliminates duplicate reporting or non-reporting, and ensures systemic collection, analysis, and public reporting of financial and outcome data to ensure that children are being served appropriately and are benefitting from those services.
3. Continue to improve strategies for **identifying infants and toddlers** who may be eligible for early intervention services (called "Child Find"), including increased outreach and communication to parents/families, physicians, hospitals (particularly neonatal units), and other referral sources.
4. Develop and implement a formal follow-up program for families of children who have been in a **neonatal intensive care unit** to ensure that they have access to information on early intervention services—not only while in the hospital but at six months and a year after birth.
5. Provide statewide training and technical assistance to ensure that early intervention providers are **trained in up-to-date, evidence-based practices** (based on peer-reviewed research).

6. Ensure that families are provided easily understood **information on the Part C complaint and appeals process** when entering the system and at review meetings.

Education

Many children, youth, and adults with disabilities require specialized services and supports in order to achieve independence and succeed in education and employment. Consistent with the last three editions of this *Assessment*, the Board recognizes efforts at the state and local levels to improve education services and supports to students with disabilities. However, there remain significant challenges with respect to educating students with disabilities for post-secondary success. Based on our findings, the Board recommends that the **Virginia Department of Education (VDOE)**:

1. Continue to support evidence-based practices to close the **growing achievement gap** on state assessments in reading and mathematics between students with and students without disabilities. Localities that do not meet targets should be required to implement corrective action plans and be provided ongoing technical assistance.
2. Rigorously enforce the Individuals with Disabilities Education Improvement Act (IDEA) requirement to ensure that students with disabilities are educated in the **least restrictive environment (LRE)** in which their Individualized Education Program (IEP) can be implemented.
3. Analyze student achievement and **outcomes as related to placements** along the continuum (including alternative schools and virtual schools/placements). Following the analysis of outcomes, determine the specific elements that contributed to student success in those settings.
4. Implement a routine monitoring process for justifications of local school system **Standards of Learning (SOL) diversion** in order to identify problem areas, provide technical assistance to localities, promote best practices, and enforce compliance. As the Commonwealth moves towards revision of current SOL assessments, it is critical that the needs of students with disabilities be an integral component of the dialogue and resulting action.
5. Develop and require a statewide, **universal Individualized Education Program (IEP) form** to ensure a more uniform set of policies and procedures, higher quality IEPs, and full compliance with federal and state laws and regulations.
6. Provide technical assistance and training to school divisions so that they are, in turn, able to educate families regarding the **importance of transition decisions**, including assessments and diploma options as early as elementary school and no later than middle school. In addition, VDOE should include a review of these activities in its statewide monitoring.
7. Develop and implement an **adult education curriculum** on the special education process for the parents and guardians of children with disabilities to help them understand their

rights and their responsibilities. This training, which should be designed to improve partnerships between schools and families, could be offered through VDOE or local school divisions. Specific topics should include (a) the transition to secondary school and to adult services, including work incentives and identification of school division representatives, and (b) the role of community services boards (CSBs), centers for independent living (CILs), and other advocacy organizations. School divisions should conduct **vigorous outreach** and marketing to ensure families know about these education and information sessions once available.

8. Revise educational **targets for achievement** for students with disabilities and other subgroups regularly. Although these require only periodic review, VDOE should consider raising achievement targets for students when targets have been met for two consecutive years.
9. Monitor and examine more closely **patterns/trends regarding discipline of students with disabilities**, including suspension and expulsion. Stricter requirements for use of positive behavioral supports should be implemented. The Board supports the legislative Commission on Youth Study (to be conducted in 2014) on the use of **seclusion and restraint** in Virginia's public and private schools and a review of how other states reduced or eliminated the use of these dangerous practices.
10. In collaboration with the Department for Aging and Rehabilitative Services, the Virginia Commonwealth University Center for Transition Innovation, and other organizations focused on transition, the VDOE should support the development and **expansion of innovative approaches to transition**. Braided funding from multiple sources engaged in ensuring that youth with disabilities enter the workforce should be explored and implemented.
11. For the small percentage of students not receiving a standard or advanced diploma (with or without credit accommodations), ensure that **students receiving the IEP diploma** (sometimes called the "special diploma") leave school either with employability skills or employment options. The diploma should convey the skills attained over the student's school career for the purpose of entering the workforce or pursuing other post-secondary activities. This effort is underway, but the specifics have not yet taken shape.
12. **Expand vocational education and training opportunities** for students with disabilities who do not wish to pursue college. These students should be provided access and opportunities equal to those provided to students without disabilities to pursue trades with instruction in integrated settings.
13. Require mandatory components in **teacher college curricula** and in continuing education for general education teachers. Training should include mandated components on collaborative teaching and learning, inclusive classrooms, diverse learning and instructional strategies, and behavioral supports.

14. **Incentivize endorsements** in special education for those seeking bachelor and advanced degrees in education.

Employment

It is critical that **integrated, competitive employment** opportunities for students with intellectual and developmental disabilities be expanded. While not every student or adult will choose employment, the choice must be there.

To facilitate this process, the Board recommends that **the Commonwealth:**

1. Provide sufficient long-term funding to **eliminate waiting lists for vocational rehabilitation**. When there are insufficient funds available, vocational rehabilitation agencies implement a federally authorized “Order of Selection,” limiting the number of individuals who can be served through the programs and prioritizing service based on severity of disability.
2. Provide funding to support replication and expansion of **innovative employment programs**, including but not limited to Project SEARCH. This will enable more individuals with ID/DD to become gainfully employed and less reliant on social security and other benefits. Programs that are developed or funded should be inclusive of individuals with significant disabilities.

The Board recommends that the **Department of Behavioral Health and Developmental Services (DBHDS) and the Department of Medical Assistance Services (DMAS):**

3. Work in partnership to modify the ID/DD Waivers to **support and incentivize integrated, competitive employment** rather than pre-vocational services, day support, and facility-based employment for eligible individuals. Changes should include
 - a. removing the rate differential that is a disincentive to competitive employment. The individual, supported employment rate should be increased to a level greater than the rate for day support programs.
 - b. placing a time limit on the use of prevocational services so that individuals who are able and wish to move into employment do not languish in prevocational services. The maximum time limit should be flexible enough to enable an individual to return to prevocational services should he or she lose a job and need additional skills training to regain employment.

The Board recommends that **HHR Secretariat agencies:**

4. Ensure that employment-related **service definitions** are consistent with state regulations unless federal mandates do not permit modification.
5. Provide clear delineation of **lead responsibility** as a standard operating procedure when multiple disability agencies are serving an individual to ensure that the individual is

receiving the employment services and supports for which he or she is eligible and that the level, intensity, timeliness, and quality of those supports are appropriate.

6. Work with the State and fellow service providers to **promote MEDICAID Works and other work incentive programs**. Ongoing training in work incentives should be provided to local agency staff and providers.

The Board supports the employment-related recommendations made by the **Human Services Research Institute (HSRI)** in their Phase I study of Virginia's ID/DD Waivers for the Virginia Department of Behavioral Health and Developmental Services (DBHDS). The Board highlights the following recommendations among the many in the report:

7. Improvements to waiver provider requirements that directly address **workforce development** are warranted. Revise the Department for Aging and Rehabilitative Services (DARS) and ID/DD Waiver provider requirements to allow for best practice and individualized approaches to employment, rather than relying on Commission for Accreditation of Rehabilitation Facilities (CARF) standards.
8. Develop a **reimbursement rate methodology** for pricing employment services [use the State Employment Leadership Network (SELN) Funding toolkit as a reference] to increase access to integrated employment services for people with ID/DD.
9. Revise employment **service definitions** to separate individual-supported employment from group-supported employment.
10. Focus on employment in the **person-centered planning process**, and increase training for case managers and service coordinators to improve their ability to help recipients reach their employment goals.
 - a. When developing an **Individual Service Plan**, discussion with the individual of his or her career interests and the services that the individual needs to achieve integrated employment must be the priority before determining what type of HCBS day or employment services the individual is authorized to receive.
 - b. For individuals currently in **state Training Centers**, consideration of each individual's interest in employment should be determined prior to any discussion of where the person will live.

The Board encourages the Commonwealth to fund and otherwise support the following SELN initiatives:

11. Develop and implement a data system that will provide **meaningful employment outcome data** (not just service utilization) on a statewide and local level. Meaningful data is critically needed to establish current performance, to identify future benchmarks for employment of individuals with disabilities, and to drive effective decision-making.
12. Develop and conduct **ongoing staff training and technical assistance** for state and local agency staff that serve individuals with disabilities, particularly local social service

agencies and public school transition personnel who may be the first point of contact regarding employment options for many individuals with disabilities.

Health Care

Health and wellness are critical to everyone's quality of life, and an adequate supply of skilled, **quality health care, residential, and habilitation providers** statewide remains critical to improving access to services for Virginians with disabilities or significant impairments. The Board recommends that the **HHR Secretariat agencies**:

1. Work in partnership with state medical/nursing/dental schools on a systematic initiative to **monitor and expand future provider capacity, especially for individuals with ID/DD**. This initiative should include but not be limited to:
 - a. developing long-term, interagency strategies to (i) **improve medical school training and externships** for doctors, nurses, dentists, and dental hygienists, (ii) **expand the number of health care providers** who are skilled and willing to serve these populations, and (iii) **include tracking mechanisms** to identify available providers statewide and by region.
 - b. developing an ongoing monitoring system to evaluate the impact of Medicaid **reimbursement rates** on provider capacity.
 - c. developing a vision and strategic plan to specifically address **unmet health care and dental needs** in rural areas and localities that have high proportions of individuals who are reliant on Medicaid, uninsured, or under-insured. This effort should include data analysis to determine specific local or regional needs, service barriers, and access issues, including the availability of adequate provider and case manager training on available services for individuals with disabilities and their families.

The Board supports and commends the legislative Joint Commission on Health Care (JCHC) for its ongoing studies to improve the availability of and access to **health and dental services**, especially "safety net" services. The Board recommends that the **Joint Commission on Health Care**:

2. Include consideration of **providers' capacity to serve** individuals with ID, DD, or other disabilities. This capacity includes not only training of medical personnel but also having accessible equipment and examination tables.

The Board recommends that the **Department of Behavioral Health and Developmental Services**:

3. Complete and publish a formal action plan for implementation of the **Developmental Disabilities Health Network** (formerly the Regional Community Supports Centers or RCSCs) to include an information and outreach component. The Board urges increased collaboration with key stakeholders, including but not limited to (a) the Virginia

Department of Health (VDH), (b) the Department of Medical Assistance Services (DMAS), (c) the state teaching medical centers, and (d) statewide, professional health care organizations and associations.

Medicaid

Because so many individuals who have a disability or are elderly rely on Medicaid as their primary health insurance, changes in this program have systemic impact on service access, availability, and delivery. The following recommendations focus on improving Medicaid program effectiveness and sustainability as well as service access, availability, and quality.

The Board supports the current efforts to redesign Virginia's **Home and Community Based Services (HCBS) ID, DD and Day Support Medicaid Waivers**. These redesigns must address not only today's needs but also the needs of a service system that must build increased community capacity and competency in the years to come.

With the recognition that significant work is likely to have been completed before this *Assessment* is published, the Board recommends that **the Commonwealth:**

1. Design waivers that reflect opportunities for increased **individual control of service dollars and budgets**. A state definition for the terms "individual resource allocation" and "individualized budgets" should be adopted as state agencies, providers, individuals with disabilities, and advocates interpret these terms differently. Individualized budgets should not have low, fixed-dollar caps on service plan authorization amounts that do not meet the service and supports needs of recipients.
2. Fund **pilot projects** of the most promising models for individual resource allocation/budgeting to avoid known issues, identify unexpected problems, and the potential for misuse of resources.
3. Allow for increased **consumer direction of services** (within Medicaid regulations), whereby individuals select their own providers and manage caregivers, and not limit consumer-directed services to personal attendant, respite, and companion services.
4. Resolve existing barriers within Virginia's HCBS Medicaid Waivers in a manner that ensures appropriate services and supports are provided to individuals in a **cost-effective** manner. This includes addressing rate disincentives, transportation restrictions, and service limitations.
5. Maintain **choice in case management providers** for all waiver recipients. [The Board does not agree with the Human Services Research Institute (HSRI) recommendation from the waiver study it conducted for Virginia that local Community Services Boards be the sole provider of case management services.] CSBs should be one of many choices that individuals receiving ID/DD Waiver services have. The Board recognizes that work in this area is ongoing.

6. Resolve the significant differences between the wait list systems for the current ID and DD Waivers. A **statewide wait list system** that is fair and equitable for all individuals requiring services should be established. The current definition of “urgent” versus “non-urgent” in the ID Waiver is inadequate. As written, “urgent” criteria do not reflect true emergency status since there are over 3,600 people on the urgent wait list.

In additional areas related to the delivery of long-term care services and supports to individuals with ID/DD, the Board recommends that **the Commonwealth:**

7. Delay plans for the **expansion of coordinated care** to Medicaid enrollees with an intellectual or other disability who receive supports under the ID or DD Waivers as long as needed to ensure thoughtful planning, research, and stakeholder input.
 - a. Initiate a process whereby the Departments of Medical Assistance Services (DMAS) and Behavioral Health and Developmental Services (DBHDS) perform due diligence in identifying the **outcomes and challenges** for the ID/DD population that resulted from coordinated/managed care efforts in other states (Kansas as one), and examine the potential impact on capacity and current ID/DD service providers. Barriers identified in other states should be addressed prior to mass enrollment of ID/DD Waiver recipients into coordinated care.
 - b. Implement small, regional **pilot programs** to identify and address Virginia-specific barriers.
 - c. Make **consumer-directed services and person-centered practices** foundational philosophies for care coordination initiatives.
 - d. Analyze **outcomes** of care, including satisfaction outcomes, provided to individuals with ID/DD who were receiving services through the Elderly or Disabled with Consumer Direction (EDCD) Medicaid Waiver and opted in to the Care Coordination Model.

The Board also recommends that the **Department of Medical Assistance Services (DMAS):**

8. Add comprehensive **dental coverage** for adults under the Medicaid State Plan. If not added as a State Plan service, dental care should be at a minimum added as a service under the new ID/DD Waiver as lack of preventive dental care has been identified as a contributing factor to rising health care costs.
9. Seek funding to develop a **dental demonstration pilot project** that will (a) improve hospital documentation and reporting of emergency room use for dental conditions; (b) either replicate or adapt the Virginia Commonwealth University ER triage model to include counseling and referral to appropriate safety net dental service providers and, when applicable, to the national Healthcare Exchange or Medicaid for insurance coverage; and (c) track changes in ER use for dental care over time. This pilot could not only reduce ER use for dental care but also may reduce health care costs over time as

individuals become familiar with and use less expensive community services for dental care.

10. Create and operate a centralized service **call center for complaints** about Medicaid services. Having a call center will provide DMAS with direct and timely feedback from Medicaid enrollees on service delivery problems and performance issues and will enable more responsive corrective actions.

Community Living Supports

In addition to its recommendations regarding Virginia’s Home and Community Based Medicaid Waivers—key community supports for persons with ID/DD—the Board makes the following additional recommendations with respect to community-based services and supports. The Board recommends that the **Department of Behavioral Health and Developmental Services (DBHDS)**:

1. Continue to monitor and examine administration of the **Individual and Family Support Program (IFSP)** for individuals with disabilities on the ID or DD Medicaid Waiver wait lists to ensure that future fund awards are used to address needs that will **prevent institutional placement**, strengthen families, and support community living. To further this effort, DBHDS should:
 - a. Ensure that **program information and the application** itself are easily accessible to individuals and families throughout the Commonwealth, including those who do not have computers or case managers to inform them about the availability of funds.
 - b. Develop clearer selection and funding criteria. Although a first-come, first-served basis may still be needed to structure application reviews, it should not be a criteria for selection for an award. **Needs-based priorities** should be identified as criteria based on the IFSP design in the DOJ Settlement Agreement and services covered under the Medicaid Home and Community Based Waivers. Services that are readily available to individuals or families through another source (Medicaid, Medicare, private insurance, etc.) should not be a priority for funding.
 - c. Distribute funds on a **semi-annual or quarterly basis** and establish a “set-aside” amount of IFSP funds for **emergency situations**, for which applications can be made during the year. Clear, objective criteria for “emergency needs” must be developed and implemented.
 - d. Designate a **team of conflict-free individuals** to review and prioritize awards based on the new criteria.
2. Work with other relevant agencies of the Commonwealth to eliminate the current **organizational conflict-of-interest issues** regarding Community Services Boards (CSBs) that provide both case management and services. Responsibility for providing case management services must be separate from the responsibility of providing direct services and supports, determining individual funding or service levels, and evaluating

services and supports. The Board recognizes that there are CSBs that have already addressed this concern and do not provide direct services.

3. Consider adopting the National Council on Disability's (NCD) **core characteristics of conflict-free case management**, which were identified by the Centers for Medicare and Medicaid Services' program guidelines and regulations for long-term care and are as follows:
 - a. Responsibility for providing case management services must be **separate** from responsibility for providing direct services and supports or determining individual funding or service levels.
 - b. Staff who conduct evaluations and assessments or develop individual plans of care cannot be **related by blood or marriage** to the individual or to any of the individual's paid caregivers.

As noted by the NCD and the aforementioned guidelines and regulations, **effective case management** requires up-to-date knowledge of (a) state, regional and local resources that can support an individual with disabilities and (b) a true understanding and commitment to the principles of person-centeredness, community integration, and community inclusion.

To improve services and address **unmet needs of youth at risk** (including those with disabilities who are in foster care or in adoption assistance programs), the Board recommends that key agencies, including (at a minimum) **DBHDS, the Office of Comprehensive Services, the Department of Juvenile Justice, and the Virginia Department of Social Services' Foster Care Division**:

4. Proactively develop and implement a **comprehensive plan** for service referrals and behavioral interventions at earlier stages to prevent hospitalizations, loss of placements, or incarceration. This comprehensive plan should include identification of service gaps, transition issues, improvements to interagency collaboration, funding needs, and infrastructure needs.

The Board further recommends that **DBHDS**:

5. Develop an **integrated, statewide crisis intervention system** that ensures service access regardless of diagnosis(es), type of disability, age, or locality of residence. The Board supports Governor McAuliffe's recent creation of a taskforce to improve mental health services and crisis intervention. The Board urges that this taskforce include crisis intervention for Virginians with ID/DD and challenging behaviors or anyone with co-occurring disorders to support person-centered policies and practices, reduce complexity, and improve accountability. **Crisis services for children** should be developed and implemented without delay.

6. Revise current licensure regulations to create a distinct set for ID/DD providers. Licensure regulations are currently all encompassing, being a single set of regulations to cover services for very diverse populations: individuals receiving mental health, substance abuse, and/or ID/DD services. Each disability group has a unique array of service values, principles, and intervention models. The regulations should be reorganized to have a set of **core requirements applicable to all** facilities or services for quality assurance, person-centered principles and for individual health and safety (among others). However, there should be **distinct, specific licensure regulations applicable for each disability population**, which include attention to service and quality-of-life outcomes. An example of licensure regulations specific to ID/DD services was implemented in Massachusetts.

The Board recommends that **the General Assembly:**

7. Approve higher funding levels for **Centers for Independent Living (CILs)** that will enable current CILs to expand service capacity and provide for the development of new CILs in under-served or unserved areas of the State.
8. Expand annual appropriations for the **Public Guardian and Conservator Program** to eliminate waiting lists for those who do require guardianship and to improve the use of currently limited mechanisms for supported decision-making.

The Board recommends that **the Supreme Court of Virginia:**

9. Ensure **civil rights protections** of individuals with ID/DD by developing an annual training initiative for lawyers and circuit court judges on guardianship and conservatorship, to include (a) appropriate assessment and identification of individual capacities/abilities for various life decisions and (b) the use of supported decision-making options such as limited guardianships, powers of attorney, and other available mechanisms that do not remove an individual's civil rights.

Institutional Supports

Regarding institutional services, the Board recommends that **the Governor and General Assembly:**

1. Eliminate the dual system of services by continuing to support and implementing the **closure of three of the four remaining state Training Centers** in a well-planned way that ensures appropriate community infrastructure and services. The closures will facilitate the provision of **quality, community-based alternatives** that will sustain and support individuals with ID/DD in the most integrated settings appropriate to their needs.
2. Develop a strategy to **eliminate the institutionalization of individuals under the age of 21** and task the Department of Medical Assistance Services (DMAS) and the Department of Behavioral Health and Developmental Services (DBHDS) with the responsibility to

develop processes that ensure adequate services are provided to these youth and their families.

3. Pass legislation to require a **Certificate of Public Need (COPN)** for both the development of **new ICFs/IID** of more than 6 beds or for **expansion** of a current ICF/IID location by more than 6 beds. Current regulations only require a COPN if a new ICF/IID or an expansion is over 12 beds. New regulation should require ICF/IID developers to demonstrate that (a) an ICF is the only way to meet the needs of individuals with disabilities in their communities, (a) the ICF is the most integrated setting appropriate for those individuals, and (c) its operations will enable individuals to fully participate in their communities.
4. Closely monitor the rapidly rising costs of services through non-state-operated ICFs/IID and **discourage the use of the ICF/IID model** while consistently promoting more integrated, independent living settings, consistent with the Settlement Agreement. If feasible, re-examine the formula or methods by which **allowed costs** are determined.

As state agencies that fund, license, or monitor non-state-operated institutions, including group (waiver) homes, intermediate care facilities for individuals with intellectual disabilities (ICFs/IID), assisted living facilities, and nursing facilities, the Board recommends that the **Virginia Departments of Health, Aging and Rehabilitative Services, and Behavioral Health and Developmental Services:**

5. Partner in an ongoing initiative to develop and implement a common method and operational definitions by which to **identify and track** individuals residing in or admitted to institutions and to analyze admission trends and factors leading to admission.

The Board further recommends that state disability agencies, including the **Departments for Medical Assistance, Aging and Rehabilitative Services, and Behavioral Health and Developmental Services:**

6. Eliminate **barriers to transitioning from institutions** to the community, including those related to access to environmental modifications or assistive technology. Existing caps on those services should be reviewed to determine if they create further barriers to community living. The Board recommends examining how other states have dealt with these barriers, including states that have used Medicaid administrative funding to cover transition costs.

To promote transparency, the Board recommends that the **Virginia Department for Health (VDH) and DBHDS:**

7. Be required to routinely post on their website those **institutions/providers that have provisional and/or revoked licenses** or have had deficiencies in clinical and safety requirements. Both agencies additionally should list the **parent owners** or organizations

that operate multiple facilities to enable public comparison of potential trends regarding violations by a particular organization or owner, not just by single facility.

The Board recommends that **DMAS, DBHDS, VDH, and the Department of Social Services (DSS)**:

8. Develop and implement an action plan to revise and update the **Uniform Assessment Instrument (UAI)**, which was developed over 20 years ago. Assessments used in Virginia should be consistent with current federal and state policies as well as **person-centered principles**. There should be required training and regular certification of UAI screeners (at least every 3 years). Procedures should be in place to ensure that UAIs are conducted and submitted to DMAS in a timely fashion. UAI revision should include key stakeholders.

The Board further recommends that the **VDH Office of Licensure and Certification**:

9. Conduct a systemic case review of individuals with ID or DD placed in nursing facilities to ensure that all have a completed, **current Uniform Assessment Instrument (UAI)** in their file. Lack of a UAI creates unnecessary obstacles to appropriate services and supports and causes discharge delays.

The Board recommends that **DMAS, VDH, DARS, DBHDS, Local Contact Agencies (LCA) and Centers for Independent Living (CILs)**:

10. Work together to examine how well the **Return to Community Assessment** (Section Q-MDS) is being implemented to identify trends by facility and by parent owner/organizations over time in terms of referrals and transitions from nursing facilities to the community. The following specific issues should be examined:
 - a. the number of individuals identified as expressing an interest in learning more about the community options in Section Q;
 - b. whether individuals expressing that interest were/are being referred to LCAs and other local agencies (CSBs, CILs, and others) to initiate that process;
 - c. the scope, appropriateness and frequency of training on Section Q referral information and expectations for the Money Follows the Person (MFP) program.

In support of recommendation 10 above, the Board also recommends that the **VDH Office of Licensure and Certification**:

- d. provide follow-up and technical assistance, as indicated, to facilities that have had no or few referrals to an LCA to determine the reasons.

The Board further recommends that **DBHDS**:

11. Improve the quality and timeliness of information available to individuals with disabilities (and their families or guardians and providers) who are transitioning from the state Training Centers. Frustrations over problems with transition processes that could have been avoided have been expressed, particularly by providers. **Critical information**, which has been provided slowly, included the status of “**exceptional rates**” and **bridge funding**.

Finally, with noted qualifications, the Board supports the following recommendations made by the **Independent Reviewer (IR) of the US Department of Justice Settlement Agreement**:

12. Personal Support Teams should develop Individual Service Plans (**ISPs**) for **transitioning individuals** that describe all community services and supports available to the individual. Individuals should be provided with a choice of all options, including those that would provide services in the most integrated setting.
13. ISPs should be **skill-based**. Many individuals with ID, DD or other disabilities need assistance to develop the independent living, social, employment, or other skills necessary to ensure maximum success in the community. However, the Board recognizes that some individuals may not need or want additional skills training and may simply want to live lives that are meaningful to them. ISPs should **include personal choice** regarding the type and level, if any, of skill development to be implemented.
14. **Discharge plans** for Training Center and other institutions’ residents should focus first on what the **individual wishes** to do in the community, including participation in employment and/or integrated day activity programs. Community placements should be sought that will enable the individual to achieve those preferences. However, the Board also believes that additional training of Center and community staff in **person-centered practices** may be warranted to improve ISPs and personal outcomes.

Community Housing

To expand the availability of affordable, accessible housing options for Virginians with disabilities, the Board recommends that the **Health and Human Resources Secretariat**:

1. Enhance and sustain cross-Secretariat collaboration to implement Virginia’s **Housing Plan to Increase Community Living Options** developed in response to the Commonwealth’s Settlement Agreement with the US Department of Justice (DOJ).
2. Develop a mechanism that targets state and federal housing funds to address critical funding gaps to (a) make **private capital investment** for the expansion of affordable housing feasible and (b) provide a **state rental subsidy** for Virginians with disabilities who choose to live in the community in their own home/apartment with rights of tenancy.

The Board recommends that the **Virginia Housing Development Authority (VHDA) and other public housing agencies (PHAs)**:

3. Adopt and implement a **Housing Choice Voucher program** for DOJ Settlement Agreement target populations. Federal approval has already been provided to VHDA to do just that.

The Board recommends that the **HHR Secretariat, in collaboration with the Commerce and Trade Secretariat:**

4. Develop and implement **statewide education and outreach strategies** to inform builders, developers, realtors, housing counselors, elected officials and community organizations about the Fair Housing Act and the need to increase capacity for the meaningful choice of integrated community living by individuals with disabilities.

The Board recommends that the **Department of Professional and Occupational Regulations within the state Office of Fair Housing:**

5. Rigorously **enforce compliance with the Fair Housing Act** and related laws.

The Board further recommends that the **HHR Secretariat agencies:**

6. Continue to explore and to increase opportunities for choice in housing options available to **Auxiliary Grant (AG) recipients**. Active engagement with the Social Security Administration regarding the expansion of choice in the SSI supplement program should be a priority. This state SSI supplement program is restrictive and needlessly segregates people.

Transportation

To increase the availability and reliability of transportation for individuals with disabilities statewide, the Board recommends that the **Department of Medical Assistance Services (DMAS):**

1. Develop and implement more rigorous service **quality and satisfaction metrics** to better measure service quality response times, and utilization trends for non-emergency Medicaid transportation services. (Trust, but verify.) The current broker's (LogistiCare) Client Satisfaction Study is inadequately designed to determine areas of needed improvement or service deficiencies; its findings are dramatically different from the number and frequency of complaints received by advocacy agencies.

Given the critical importance of Medicaid funded non-emergency transportation for Virginians with disabilities and those who are elderly, the Board recommends that **the General Assembly:**

2. Reconsider **authorization of a Joint Legislative and Audit and Review Commission (JLARC) study** similar to HJ 40, which failed in the 2014 General Assembly, to examine program effectiveness and areas for improvement in the 2015 session. In the

alternative, the Board recommends that the Administration contract out for a similar study to be conducted.

The Board further recommends that **the Commonwealth:**

3. Provide **incentives for localities to designate matching funds** for federal transportation dollars on a sustainable, long-term basis. The cost to a locality/region to sustain public and paratransit is significant. Para-transit services in particular are highly subsidized. When user demand increases, so does the cost to the locality, which can be a disincentive to expand service.
4. Promote and provide incentives that facilitate **coordinated community development** linking housing, transportation and services. Coordinated planning activities in localities or regions have improved, but continued vigilance is needed.

Finally, the Board recommends that both the **Medicaid Transportation Advisory Committee (MTAC)** and the **State Agencies Coordinating Transportation workgroup (SACT)**, led by the **Department of Rail and Public Transportation:**

5. Re-establish **regular meetings and communication**. Doing so will promote identification of emerging issues as well as development of systemic strategies to increase/improve transportation services.

II. Key Findings and Recommendations

This section provides summaries of the Board’s findings for each of nine service areas assessed. It provides additional detail and context for the recommendations listed above, which are also included by service area here. These findings are provided in the chapter order that the reader will find in **Volume 2**, (the complete *2014 Assessment of Disability Services in Virginia*), beginning with early intervention services.

A. Early Intervention

Evidence clearly shows that infants and toddlers with disabilities who receive services and supports at adequate levels when diagnosed with a chronic condition have better outcomes than children who do not receive services early in life. In some instances, medical costs are lower over time for those who received timely services than for children who did not. **Early intervention (also known as “Part C services”)** can reduce functional impairments later in life, thereby increasing the individual’s capacity for self-sufficiency. Ideally, lifespan supports begin at initial diagnosis, and screening for developmental delays or other disabilities occurs as part of *routine* pediatric medical screenings.

For many years, Virginia lagged behind other states in identifying infants and toddlers from **birth to age three** who needed early intervention services, and especially from birth to one year. Virginia is now in compliance on this factor and is serving significantly more infants and toddlers at an early age, a positive development. In federal fiscal year (FFY) 2011 (the latest data available), Virginia exceeded its state target for identifying babies, from birth to one year, who needed intervention services and raised the target for FFY 2012. The increases were due primarily to these actions: (1) established prematurity as an automatic eligibility criterion, (2) conducted training and technical assistance for local systems and providers, and (3) collaborated with the Department of Health to ensure early identification of children with hearing loss or congenital anomalies.

Insurance reimbursement barriers were also addressed. Outreach was conducted to **hospital neonatal intensive care units (NICU)** in Virginia and in the District of Columbia to increase referrals of preterm infants to Part C services (a Board recommendation in its 2011 *Assessment*). An outreach initiative with hospitals in the Central Virginia region, designed to ensure follow up with families whose children were in the NICU, began in June of 2014.

The establishment of the **Medicaid Early Intervention Program** also increased access to Part C services. This program includes reimbursement for targeted case management or service coordination for all children dually enrolled in Medicaid and Part C. The number of Part C Medicaid providers has increased exponentially. In state fiscal year (SFY) 2009, of the total infants and toddlers served by Part C (11,766), only 2,830 (approximately 24 percent) were enrolled in Medicaid. In SFY 2013, the number and proportion of children enrolled in both

Medicaid and Part C dramatically increased to 9,212 children, or 59.4 percent of the 15,523 children served.

Virginia's Part C program, however, continues to be **underfunded**, and there is **wide variability in services** between localities. Funding levels were briefly increased in 2010 and 2011 due to the availability of federal stimulus funds from the American Recovery and Reinvestment Act. In SFY 2013, 26 out of 40 Part C programs statewide that requested additional funds could not be helped. In 2012 and 2103, **wait lists** for Part C services were established in 8 localities, a violation of the Individuals with Disabilities Education Improvement Act (IDEA). Responding to concerns about the Commonwealth's inability to meet federal Part C standards, the legislature allocated \$2.2 million in state General Funds in SFY 2013 and an additional \$6 million for SFY 2014 to address the compliance issue. Unfortunately, state fund increases have been accompanied by a decrease in the number of localities opting to provide local funding. Thus, long-term sustainable funding for these critical services has not been achieved, particularly since the number of children served will likely continue to increase.

As noted in the last three editions of this *Assessment*, beginning in 2006, an ongoing challenge has been obtaining **reliable, accurate data** on Part C service **utilization and expenditures**. While there have been some improvements in program, revenue, and expenditure reporting, continuing problems exist with inconsistent local reporting, duplicate reporting, and changes in the way data is reported from year to year. This makes accurate reporting and trend analysis difficult, if not impossible. Further, there is no unified system to report the **outcomes** of children who have received services through Part C.

The Department of Behavioral Health and Developmental Services (DBHDS) has been transparent about reporting data problems in its annual reports to the General Assembly. However, it does not appear that sufficient efforts have been made to fix the problems. As an example, in SFY 2012, the reported expenditure for speech language pathology was noted to be \$18 million, up from \$8.2 million in SFY 2011 and \$8.4 million in SFY 2013. There was no explanation for the discrepancy, but it was noted that it was not a typographical error.

Federal outcome indicators assess social and emotional progress, skills and knowledge, and appropriate behavior. Virginia shows significant improvement in those areas for participating children (as would be expected). However, actual performance did not meet established targets. Performance for federal fiscal year (FFY) 2011, the latest year for which data was available, was comparable to FFY 2010. To address slippage in two of the indicators, additional resources on evidence-based practices were provided to local systems as was support to address quality data collection. Revisions were made to the required Individual and Family Service Plan (IFSP), which details the services and supports provided to each child, to align the planning tool with federal child indicators. The new form became effective on July 1, 2013. Results were not yet available at the time of this assessment.

Another positive Part C initiative is the development of **regional communities of practice** that focus on coaching and mentoring. In addition, DBHDS has increased its efforts to improve communication and information sharing with providers through the use of technology and social media. DBHDS also established an **Early Intervention Family Support Network** through the Arc of Virginia and its local chapters.

Formal parental complaints and appeals with respect to Part C are minimal. It is not known whether this is due to general satisfaction with services or whether families are not aware of or knowledgeable about the **complaint system**. In FFY 2012, there were minimal complaints: only 1 due process request, 3 formal complaints, and 2 requests for mediation were made. Considering the difficulties of obtaining services for some families, including waiting lists in some localities, the low level of complaints is notable.

Public comment received by the Virginia Board for People with Disabilities for this *Assessment* indicates that while families are happy with the early intervention services, **program and service information** is not perceived as readily available or user-friendly. In communicating with families, health providers must also be sensitive to **cultural diversity** and the ways in which culture affects service 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 to providing effective services. Information must be available in a timely manner and in understandable, accessible language and format.

To provide **front-loaded supports** that maximize positive outcomes for infants and toddlers and offer the highest potential for long-range cost avoidance, Virginia's Early Intervention Services (EI) must be delivered at the earliest juncture possible. The Board recommends that the **General Assembly**:

1. **Fully fund the Part C Early Intervention System** to ensure that children are evaluated as soon as possible and have access to the level and intensity of services and supports needed as soon as eligibility is determined.

The Board further recommends that the Commonwealth, under the leadership of the **Health and Human Resources Secretariat**:

2. Improve accountability by implementing a **statewide data system** that eliminates inconsistencies in local reporting, eliminates duplicate reporting or non-reporting, and ensures systemic collection, analysis, and public reporting of financial and outcome data to ensure that children are being served appropriately and are benefitting from those services.
3. Continue to improve strategies for **identifying infants and toddlers** who may be eligible for early intervention services (called "Child Find"), including increased outreach and communication to parents/families, physicians, hospitals (particularly neonatal units), and other referral sources.

4. Develop and implement a formal follow-up program for families of children who have been in a **neonatal intensive care unit** to ensure that they have access to information on early intervention services—not only while in the hospital but at six months and a year after birth.
5. Provide statewide training and technical assistance to ensure that early intervention providers are **trained in up-to-date, evidence-based practices** (based on peer-reviewed research).
6. Ensure that families are provided easily understood **information on the Part C complaint and appeals process** when entering the system and at review meetings.

B. Education

As children progress into school, many with disabilities require specialized services and supports in order to achieve independence and succeed in education and later employment. In July of 2013, the US Department of Education, Office of Special Education Programs (USDOE-OSEP) determined that Virginia “meets the requirements and purposes of IDEA” for federal fiscal year 2011. However, consistent with the last three editions of the *Assessment*, the Board finds continued challenges with respect to the education of students with disabilities under the federal **Individuals with Disabilities Education Improvement Act (IDEA)**.

Since 2006, the date of the Board’s first *Assessment*, **K–12 education** has had many significant changes, many of which have affected students with disabilities. As with early intervention, **enrollment in preschool** can have a significant positive impact on children with disabilities. Children from low-income families who received **Head Start** preschool services had **significant achievement increases** in all assessed domains. In addition to educational progress, other valuable results for children enrolled in Head Start included (1) obtaining immunizations and other medical treatments, (2) receiving oral health examinations and treatment, and (3) being referred for and receiving mental health services. Positive results were also achieved by children who participated in preschool programs offered by local school divisions and at the Virginia School for the Deaf and Blind at Staunton.

Assistive technology can be a key to full participation in school and work. The 2012 General Assembly amended the *Code of Virginia* to allow school divisions that have purchased an **assistive technology device** for a student’s use to sell, lease, donate or loan that device when he or she exits school. This allows devices that are specialized for an individual student to move with that student under certain circumstances or to go to a state or local agency with which the student is working.

The Virginia Department of Education (VDOE) has engaged in several activities to improve K–12 education, including special education. Proposed **teacher licensure changes** (still under administrative review) would establish add-on endorsements for special education. If approved, this could increase the number of general education teachers who have the knowledge and

training to work effectively with students with disabilities. VDOE has continued to improve **teacher preparation** programs. The Department has also continued to work with school divisions to avoid **unnecessary referrals to special education**, particularly of minority students.

In 2014, VDOE launched a **new website for families** to provide information on special education issues, practices, and services. It also developed Standards of Learning (SOL) Assessment tutorials. VDOE continues to offer significant technical assistance and training activities for school personnel.

There continue, however, to be numerous **challenges** for students with disabilities and their families as they seek to ensure receipt of a free and appropriate public education (FAPE) as guaranteed under IDEA. A key component of students' success is the decision made regarding their **assessment and diploma options**. Those choices determine whether the student has full access to the general curriculum and is participating in an SOL track. It is clear that parents are not being educated in a timely manner on the implications and ramifications of these options. Many parents are unaware that if their child does not participate in the SOL Assessments, he or she will be unable to obtain a standard or advanced diploma (a "high school diploma" for the purposes of employment, higher learning, continuing education, and financial aid). Public comment from a variety of arenas indicates that parents still struggle with perceived **low expectations** for their child's performance, and that too many children continue to be directed away from the SOL track.

Families additionally voice confusion regarding the State's **accountability process**. Families report being told that they can switch back and forth from an alternate to an SOL track. However, "catching up" with peers becomes more and more unrealistic the longer a student is not participating in the SOL curriculum.

To remove one barrier, the **modified standard diploma (MSD) option** has been eliminated beginning with students entering the 9th grade in 2013–2014. The MSD was created for students who were unable to meet the credit requirements for a standard diploma, but whose academic performance was more advanced than those students who would typically be in a special diploma track. The MSD however, was not recognized by most institutions of higher education or by most employers and did not enable students to access financial aid. The legislation that eliminated the MSD requires the Board of Education to make provisions for students with disabilities to earn a standard diploma through **credit accommodations**. Although the results will not be known for several years, this effort should result in more students receiving a standard diploma.

In its *2011 Assessment*, the Board reported a "notable increase among students with disabilities in performance on standardized tests" because a reduction in the achievement gap occurred between 2006 and 2010. That trend has reversed. While all scores since 2011 for reading and math have dropped, the aggregate scores for students with disabilities decreased at a higher rate for students taking the 8th grade SOL tests. While at least part of the change is

due to an increase in the test “cut scores” (pass scores), the **increasing achievement gap** is problematic. In 2009–2010 the proficiency pass rate for students with disabilities was 70 percent for reading and 66 percent for math compared with 90 percent of all students in reading and 87 percent of all students in math. In 2012–2013, the pass rate for students with disabilities in reading was 42 percent, compared to 71 percent of all students and in math was 35 percent, compared to 62 percent of all students. Students with disabilities also continue to score the lowest among all student subgroups, including students with limited English proficiency and those classified as economically disadvantaged.

Transition to higher education and/or integrated employment (in the community) is the ultimate goal for students with disabilities. In 2013, the Virginia Department of Education completed a survey of students with disabilities who exited school after the 2010–2011 and 2011–2012 school years. Consistent in both years, about thirty-five percent of the total respondents were enrolled in some type of higher education one year post high school. However, nearly 40 percent of students were neither in higher education or competitively employed. A larger number (72 percent) were engaged in some type of employment, training, or education program, which includes non-competitive facility-based employment (“sheltered workshops”). Research, including but not limited to an October 2013 Joint Commission on Health Care report, indicates that students with autism spectrum disorders (ASD) have even poorer post-secondary outcomes than students with other disabilities, and adults with autism have poorer employment outcomes. These results are extremely concerning and are a clear indication that our system of educating students with disabilities and preparing them for adulthood is **not succeeding for a large number of students**.

VDOE has expressed significant concern about these results in a variety of venues and continues to devote significant resources to best practices in transition, including (1) opportunities for school divisions to participate in its **Virginia Transition Outcomes Project**, an annual transition conference; (2) growth in the **I’m Determined** self-advocacy program for students; and (3) establishment of the **Richmond Career Education and Employment Academy**, a small charter school (opened in September of 2013) for students with significant cognitive disabilities and academic challenges. The Academy focuses on career education and competitive employment or post-secondary training and education for participating students. Outcomes will not be available for several years post implementation, but if the model works, it could be expanded. The **Virginia Commonwealth University Center for Autism Excellence (VCU-ACE)**, established since the 2011 *Assessment*, focuses on improving outcomes for students with autism spectrum disorders. In 2013, VDOE announced its intent to fund a **Center for Transition Innovation** at the VCU Rehabilitation and Research Center, which will focus on information dissemination, online education, and implementation of best practice models among other activities. The Center opened in April of 2014; analysis of results will be several years in the future.

As with many other programs, local control of Virginia’s public education system results in **significant variability in the adequacy, level, and effectiveness of educational services**. The

recession resulted in state and local cuts to school division budgets, including special education; and in turn, resulted in fewer teacher training opportunities, reduced curriculum offerings, and less support for paraprofessionals. All of these factors potentially contribute to the widening of the achievement gap between students with and without disabilities. The **disparity between wealthy and financially restricted school divisions** becomes even more apparent during times of economic challenges and poses a major threat to meeting students' needs. While recognizing that local control is a core feature of the Commonwealth's public education system, the Virginia Department of Education (VDOE) should increase efforts to improve accountability and achievement among localities. This includes the critical area of educating students with disabilities in the **least restrictive environment**. 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. In past years, data showed that Virginia's targets for serving students with disabilities in the least restrictive environment had not been met: the number of children spending most of their day in a regular classroom remains below 70 percent.

Rates of **suspension and expulsion for students with disabilities** also remain a concern. The number of school divisions with a significant discrepancy in the rate of suspension or expulsion for greater than 10 days in a school year for students with IEPs continues to rise. Concern over the use of **seclusion and restraint** in both public and private schools prompted the General Assembly to request that the Commission on Youth, in coordination with the VDOE and the Department of Behavioral Health and Developmental Services (DBHDS), examine these practices and explore what other states have done to reduce or eliminate the use of these dangerous practices.

Many children, youth, and adults with disabilities require specialized services and supports in order to achieve independence and succeed in **education and employment**. Consistent with the last three editions of this *Assessment*, the Board recognizes efforts at the state and local levels to improve education services and supports to students with disabilities. However, there remain significant challenges with respect to educating students with disabilities for post-secondary success.

The Board recommends that **the Virginia Department of Education (VDOE)**:

1. Continue to support evidence-based practices to close the **growing achievement gap** on state assessments in reading and mathematics between students with and students without disabilities. Localities that do not meet targets should be required to implement corrective action plans and be provided ongoing technical assistance.
2. Rigorously enforce the Individuals with Disabilities Education Improvement Act (IDEA) requirement to ensure that students with disabilities are educated in the **least restrictive environment (LRE)** in which their Individualized Education Program (IEP) can be implemented.

3. Analyze student achievement and **outcomes as related to placements** along the continuum (including alternative schools and virtual schools/placements). Following the analysis of outcomes, determine the specific elements that contributed to student success in those settings.
4. Implement a routine monitoring process for justifications of local school system **Standards of Learning (SOL) diversion** in order to identify problem areas, provide technical assistance to localities, promote best practices, and enforce compliance. As the Commonwealth moves towards revision of current SOL assessments, it is critical that the needs of students with disabilities be an integral component of the dialogue and resulting action.
5. Develop and require a statewide, **universal Individualized Education Program (IEP) form** to ensure a more uniform set of policies and procedures, higher quality IEPs, and full compliance with federal and state laws and regulations.
6. Provide technical assistance and training to school divisions so that they are, in turn, able to educate families regarding the **importance of transition decisions**, including assessments and diploma options as early as elementary school and no later than middle school. In addition, VDOE should include a review of these activities in its statewide monitoring.
7. Develop and implement an **adult education curriculum** on the special education process for the parents and guardians of children with disabilities to help them understand their rights and their responsibilities. This training, which should be designed to improve partnerships between schools and families, could be offered through VDOE or local school divisions. Specific topics should include (a) the transition to secondary school and to adult services, including work incentives and identification of school division representatives, and (b) the role of community services boards (CSBs), centers for independent living (CILs), and other advocacy organizations. School divisions should conduct **vigorous outreach** and marketing to ensure families know about these education and information sessions once available.
8. Revise educational **targets for achievement** for students with disabilities and other subgroups regularly. Although these require only periodic review, VDOE should consider raising achievement targets for students when targets have been met for two consecutive years.
9. Monitor and examine more closely **patterns/trends regarding discipline of students with disabilities**, including suspension and expulsion. Stricter requirements for use of positive behavioral supports should be implemented. The Board supports the legislative Commission on Youth Study (to be conducted in 2014) on the use of **seclusion and restraint** in Virginia's public and private schools and a review of how other states reduced or eliminated the use of these dangerous practices.

10. In collaboration with the Department for Aging and Rehabilitative Services, the Virginia Commonwealth University Center for Transition Innovation, and other organizations focused on transition, the VDOE should support the development and **expansion of innovative approaches to transition**. Braided funding from multiple sources engaged in ensuring that youth with disabilities enter the workforce should be explored and implemented.
11. For the small percentage of students not receiving a standard or advanced diploma (with or without credit accommodations), ensure that **students receiving the IEP diploma** (sometimes called the “special diploma”) leave school either with employability skills or employment options. The diploma should convey the skills attained over the student’s school career for the purpose of entering the workforce or pursuing other post-secondary activities. This effort is underway, but the specifics have not yet taken shape.
12. **Expand vocational education and training opportunities** for students with disabilities who do not wish to pursue college. These students should be provided access and opportunities equal to those provided to students without disabilities to pursue trades with instruction in integrated settings.
13. Require mandatory components in **teacher college curricula** and in continuing education for general education teachers. Training should include mandated components on collaborative teaching and learning, inclusive classrooms, diverse learning and instructional strategies, and behavioral supports.
14. Incentivize **endorsements in special education** for those seeking bachelor and advanced degrees in education.

C. Employment

The challenges of finding and maintaining employment apply to all adults but are complicated for those with disabilities. The current employment service system remains fragmented and complex with various state agencies providing different employment-related services (e.g., the Department for Aging and Rehabilitative Services (DARS), the Department for the Blind and Vision Impaired (DBVI), schools, Workforce Centers, etc.). This is a considerable barrier to employment. The existing system has different points of entry, application processes, and eligibility requirements. Services available to people with disabilities, especially those with significant disabilities, are often inadequate to facilitate a person’s desire to seek and maintain employment. **Expansion of vocational rehabilitation service capacity** requires development, not only of job sites, but also of individual training, placement, job coaching, and worksite accommodations (such as assistive technology, workplace accessibility, and personal assistance services).

Budgetary issues further complicate the nature and level of employment/vocational services and supports available to individuals with disabilities. Due to insufficient funding, the

Department for the Blind and Visually Impaired (DBVI) has operated under an **Order of Selection**, which provides vocational services only to those individuals with the most significant disabilities. Currently, DBVI does not have a waiting list for services.

Until March of 2014, the Department for Aging and Rehabilitative Services (DARS) had a similar Order of Selection, which closed vocational rehabilitation (VR) services to individuals in Categories 3 and 4. Students with disabilities are affected disproportionately by any Order of Selection, since many students need these services to transition into advanced training, post-secondary education, or employment. Additional funding is also needed to replicate **innovative and successful programs**, such as Project SEARCH. This project provides internships for high school students with intellectual and developmental disabilities, including autism, and has resulted in permanent employment outcomes for many students. It is important, however, that attention is directed beyond the cadre of students who can benefit from a program like Project SEARCH; other approaches and programs must also be explored.

Virginia continues to operate many facility-based (sheltered) employment programs that neither provide a competitive wage nor help develop skills valuable to employers, which constitutes a form of segregation. This over-reliance on facility-based employment was noted by the Board in its previous *Assessments* and was identified as an issue by the US Department of Justice (DOJ) in its investigation findings. In a very positive development, the newly passed (July of 2014) federal Workforce Investment Opportunity Act places significant limits on the use of sheltered workshops for students in transition.

The 2012 Settlement Agreement between the Commonwealth and the US Department of Justice (DOJ) requires that to the greatest extent possible, Virginia provide individuals in the target populations with competitive, integrated employment activities, including supported employment. The Settlement also requires the Commonwealth to (1) maintain its membership in the **State Employment Leadership Network (SELN)**, and (2) establish a state policy on the **Employment First Initiative**, which prioritizes employment at minimum or competitive wages in integrated work settings for individuals with intellectual or developmental disabilities.

Extensive training and education for individuals with disabilities and their families, educators at all levels, state agencies, service providers, and employers is necessary—not only to change expectations about the capabilities of individuals with disabilities—but also to promote integrated, competitive employment. From 2011 to 2013, DBHDS and DARS conducted annual **statewide awareness and education** efforts on Employment First through multiple regional trainings and statewide summits. These trainings will continue in 2014.

Virginia established its **SELN** in 2009. Spearheaded by DBHDS, its membership includes, among others, all state disability agencies committed to the implementation of an Employment First Initiative. Because agencies collect data differently and the programs come from different funding streams, the SELN is working on a **system-wide data collection** and performance measurement system and procedures for employment data. It is important to establish

baseline data soon (required by the DOJ Settlement Agreement) in order to measure progress as the Employment First Initiative is implemented. The effort to address this need has been very slow to move forward.

Executive Order No. 55, signed in November of 2012 by then Governor McDonnell, directed the Virginia Workforce Council to identify and develop strategies for expanding the employment of individuals with disabilities in the Commonwealth's private sector. In doing so, the Council was required to partner with the Virginia Employment Commission, Workforce Development Services Division of the Virginia Community College System, the Departments for Aging and Rehabilitative Services, Blind and Vision Impaired, Veterans Services, Behavioral Health and Developmental Services and other experts in the employment of persons with disabilities. Between September and December 2013, eight regional workshops were held to educate private- and public-sector employers on the benefits of hiring and accommodating people with disabilities in the workplace and connect employers with regional contacts for information and service coordination.

Governor McAuliffe, who took office in January of 2014, has also indicated a strong commitment to **workforce development**, and it is hoped that his Administration will follow the lead of Governor Markel of Delaware and implement specific, tangible actions to increase employment opportunities for individuals with disabilities in the Commonwealth. Resources allocated for employment preparation are a valuable, long-term investment for the Commonwealth. Employment services to individuals with disabilities can enable them to become productive taxpayers who are less dependent on government services while employers gain hard-working, committed employees.

A concern for many Virginians with disabilities who seek employment is the potential loss of benefits, especially Medicaid, if their earnings are too high. In many cases, individuals with disabilities and their families, as well as professionals, are not fully informed about available **work incentive programs** that are designed to address such concerns. These incentives include but are not limited to: the Plan to Support Self-Sufficiency (PASS), 1619b, MEDICAID WORKS, and Impairment-Related Work Expenses (IRWE). As an example, the MEDICAID WORKS program allows individuals with disabilities to earn up to \$46,740 annually and retain up to \$33,747 in a savings account without jeopardizing Medicaid or its disability waiver services. This program has been underutilized in Virginia since its inception; however the numbers are increasing due to improved outreach.

Ongoing **information and outreach** about these programs to individuals with disabilities, their families, and disability professionals is essential to improve overall utilization of work incentives. Secondary schools and institutions of higher learning have an important role and impact in doing so. Increased coordination is indicated in developing more effective information that encourages Medicaid enrollees to participate in work incentive programs.

There is a great deal of work involved in **improving employment outcomes** for individuals with intellectual and developmental disabilities. Preparation and exploration must begin at a young age and continue throughout each individual's formative years to ensure that employment is an expectation. Virginia is economically better off than the vast majority of states and must make a **policy and financial commitment** to helping people become tax-paying citizens. To facilitate this process, the Board recommends that **the Commonwealth:**

1. Provide sufficient long-term funding to **eliminate waiting lists for vocational rehabilitation**. When there are insufficient funds available, vocational rehabilitation agencies implement a federally authorized "Order of Selection," limiting the number of individuals who can be served through the programs and prioritizing service based on severity of disability.
2. Provide funding to support replication and expansion of **innovative employment programs**, including but not limited to Project SEARCH. This will enable more individuals with ID/DD to become gainfully employed and less reliant on social security and other benefits. Programs that are developed or funded should be inclusive of individuals with significant disabilities.

The Board recommends that the **Department of Behavioral Health and Developmental Services (DBHDS) and the Department of Medical Assistance Services (DMAS):**

3. Work in partnership to modify the ID/DD Waivers to **support and incentivize integrated, competitive employment** rather than pre-vocational services, day support, and facility-based employment for eligible individuals. Changes should include
 - a. removing the rate differential that is a disincentive to competitive employment. The individual, supported employment rate should be increased to a level greater than the rate for day support programs.
 - b. placing a time limit on the use of prevocational services so that individuals who are able and wish to move into employment do not languish in prevocational services. The maximum time limit should be flexible enough to enable an individual to return to prevocational services should he or she lose a job and need additional skills training to regain employment.

The Board recommends that **HHR Secretariat agencies:**

4. Ensure that employment-related **service definitions** are consistent with state regulations unless federal mandates do not permit modification.
5. Provide clear delineation of **lead responsibility** as a standard operating procedure when multiple disability agencies are serving an individual to ensure that the individual is receiving the employment services and supports for which he or she is eligible and that the level, intensity, timeliness, and quality of those supports are appropriate.

6. Work with the State and fellow service providers to **promote MEDICAID Works and other work incentive programs**. Ongoing training in work incentives should be provided to local agency staff and providers.

In November of 2013, under a contract with DBHDS, the Human Services Research Institute (HSRI) released its Phase I study report on Virginia's ID/DD Medicaid Waivers: *My Life, My Community! Re-designing Supports for Virginians with Intellectual and Developmental Disabilities*. The report found that the Commonwealth's largest investments in employment services were in **group-supported employment**. In addition, they found that individuals with ID/DD were not seen as being able to work and, thus, were directed toward work enclaves, other group employment, or day programs. The Board supports the HSRI recommendations and highlights several of them:

7. Improvements to waiver provider requirements that directly address **workforce development** are warranted. Revise the Department for Aging and Rehabilitative Services (DARS) and ID/DD Waiver provider requirements to allow for best practice and individualized approaches to employment, rather than relying on Commission for Accreditation of Rehabilitation Facilities (CARF) standards.
8. Develop a **reimbursement rate methodology** for pricing employment services [use the State Employment Leadership Network (SELN) Funding toolkit as a reference] to increase access to integrated employment services for people with ID/DD.
9. Revise employment **service definitions** to separate individual-supported employment from group-supported employment.
10. Focus on employment in the **person-centered planning process**, and increase training for case managers and service coordinators to improve their ability to help recipients reach their employment goals.
 - a. When developing an **Individual Service Plan**, discussion with the individual of his or her career interests and the services that the individual needs to achieve integrated employment must be the priority before determining what type of HCBS day or employment services the individual is authorized to receive.
 - b. For individuals currently in **state Training Centers**, consideration of each individual's interest in employment should be determined prior to any discussion of where the person will live.

The Board encourages the Commonwealth to fund and otherwise support the following SELN initiatives:

11. Develop and implement a data system that will provide **meaningful employment outcome data** (not just service utilization) on a statewide and local level. Meaningful data is critically needed to establish current performance, to identify future benchmarks for employment of individuals with disabilities, and to drive effective decision-making.

12. Develop and conduct **ongoing staff training and technical assistance** for state and local agency staff that serve individuals with disabilities, particularly local social service agencies and public school transition personnel who may be the first point of contact regarding employment options for many individuals with disabilities.

D. Health Care

Virginians, with or without disabilities, who have health insurance (private, Medicaid, or Medicare) can obtain direct **health services** from a variety of providers and practitioners. Regional differences exist in the availability and accessibility of providers, however. For those without insurance or who are under-insured, **“safety net” resources for health and dental care** have included local health departments, Federally Qualified Community Health Centers, which are non-profit organizations, and local Free Clinics, staffed by volunteers, which primarily serve adults.

Since SFY 2000, state funding for the Virginia Department of Health (VDH) has declined and was only 25 percent of VDH’s annual budget in SFY 2013. In 2011, VDH, with stakeholder input, developed and implemented plans to **decrease the number of local health clinics and dental clinics** that it staffs and funds. VDH initiated these efforts to move the agency away from clinical services to a preventive model of services, and to address the fiscal sustainability of the clinics. However, as of the end of SFY 2013, VDH had not posted any information or reports on these plans.

VDH has closed several **Child Development Clinics (CDCs)** that provided diagnostic assessment, and treatment/care and planning for children suspected of having a developmental delay or disability, learning problems, or behavioral or emotional problems. Closures of local health clinics and CDCs have significant implications for **access to preventive services** and have **affected access to screenings** for certain Medicaid waivers.

A health care resource available specifically for Virginians with an intellectual disability (ID) has been the **Regional Community Support Centers (RCSCs)**, outpatient clinics operated through the state’s five Training Centers (institutions). The RCSCs have been funded by state appropriations to the Department of Behavioral Health and Developmental Services (DBHDS). Initiated in Northern Virginia in 1998, funding to expand the RCSCs to all five Training Centers occurred in SFY 2008. The RCSCs were charged with providing clinical and health services that were unavailable or not accessible in each region. Service priorities were based on regional service needs and gaps through collaborative planning by local Community Service Boards (CSBs) and other community stakeholders. As a result, the scope and type of service available at each RCSC varied. The RCSC target populations have been individuals with ID discharged from a Training Center to the community and individuals living in the community who are referred by their CSB. The RCSCs also provided training to medical or health care students and to community professionals on serving individuals with ID, thereby expanding the trained workforce.

All five RCSCs provided preventative dental care, which is not a covered service for adults under Medicaid, as well as more complex dental care, as indicated. Only two RCSCs, both located in rural and underserved areas, provided neurological services; three provided medical services; and four provided psychological or psychiatric services (assessment, consultation and treatment). DBHDS only was able to provide RCSC utilization data for SFY 2012. Statewide that year, a total of 2,862 individuals received dental services; 432, neurological services; 503, medical services; 229, psychological services; and 259, psychiatric services. In addition, in SFY 2012, a total of 925 staff in community residential or health care settings were trained, and a total of 177 interns in various health care or related fields were trained.

In the DOJ Settlement Agreement, the Commonwealth made a commitment to expand community service capacity and to strengthen efforts to ensure the health and safety of individuals with ID/DD living in communities. In January of 2014, DBHDS announced plans to transform the RCSCs by moving them into the community and expanding outpatient services through public/private partnerships. This new system is the **Developmental Disability (DD) Health Support Network**. At time of publication, DBHDS was developing a formal report on the transition and future network configuration, which will be released later in 2014.

There is continued concern by advocates, legislators, and others about the adequacy of the health and dental “safety net” services. Since 2012, the **Joint Commission on Health Care (JCHC)** has explored that issue along with several other issues: financial impact of untreated dental disease on Medicaid expenditures and hospital emergency room costs; factors contributing to rising health care costs; tele-medicine; and the workforce capacity statewide of various health care providers. Due to population growth, especially the proportion of elderly, the future needs for medical personnel in Virginia are expected to exceed workforce availability in coming years. The number of physician residency slots has been static in relation to demand. Moreover, localities that are rural or have high poverty rates have consistently had difficulty over time attracting health care providers. The JCHC additionally completed a two-year study (HJR 82) on the feasibility of developing Chronic Health Care Homes, often referred to as **patient-centered medical homes (PCMH)**. A PCMH provides team-based care led by the individual’s personal physician; the team is responsible for planning and delivering care for “the whole person” based on individual needs.

The legislative Joint Commission on Health Care (JCHC) and the Joint Legislative Audit and Review Committee (JLARC) have conducted studies on the actual **access to and availability of services for individuals who are low income and enrolled in Medicaid**. A 2012 JLARC study on the impact of Medicaid reimbursement rates found that (1) the proportion of providers who participate in Medicaid varies considerably by specialty, and (2) rural areas have the lowest access to Medicaid providers. For example, only 34 percent of all dentists licensed to practice in Virginia accept Medicaid. A more general concern has been the current and future supply of skilled, quality health care, residential and habilitation providers statewide. Having an adequate number of providers remains critical to improving access to services for Virginians with any disability or significant impairment.

The Board recommends that the **HHR Secretariat agencies**:

1. Work in partnership with state medical/nursing/dental schools on a systematic initiative to **monitor and expand future provider capacity, especially for individuals with ID/DD**. This initiative should include but not be limited to:
 - a. developing long-term, interagency strategies to (i) **improve medical school training and externships** for doctors, nurses, dentists, and dental hygienists, (ii) **expand the number of health care providers** who are skilled and willing to serve these populations, and (iii) **include tracking mechanisms** to identify available providers statewide and by region.
 - b. developing an ongoing monitoring system to evaluate the impact of Medicaid **reimbursement rates** on provider capacity.
 - c. developing a vision and strategic plan to specifically address **unmet health care and dental needs** in rural areas and localities that have high proportions of individuals who are reliant on Medicaid, uninsured, or under-insured. This effort should include data analysis to determine specific local or regional needs, service barriers, and access issues, including the availability of adequate provider and case manager training on available services for individuals with disabilities and their families.

The Board supports and commends the legislative Joint Commission on Health Care (JCHC) for its ongoing studies to improve the availability of and access to **health and dental services**, especially “safety net” services. The Board recommends that the **Joint Commission on Health Care**:

2. Include consideration of **providers’ capacity to serve** individuals with ID, DD or other disabilities. This capacity includes not only training of medical personnel but also having accessible equipment and examination tables.

The Board recommends that the **Department of Behavioral Health and Developmental Services**:

3. Complete and publish a formal action plan for implementation of the **Developmental Disabilities Health Network** (formerly the Regional Community Supports Centers or RCSCs) to include an information and outreach component. The Board urges increased collaboration with key stakeholders, including but not limited to (a) the Virginia Department of Health (VDH), (b) the Department of Medical Assistance Services (DMAS), (c) the state teaching medical centers, and (d) statewide, professional health care organizations and associations.

E. Medicaid

A key funder of health care and long-term care services is **Medicaid**. Medicaid is a **publicly funded health insurance program** that is jointly administered and funded by the US Centers for Medicare and Medicaid (CMS) and each individual state. Many Virginians rely on Medicaid as their health insurance, which enables them to receive basic preventive and wellness or related medical services. There were 1,147,788 individuals enrolled in Medicaid in SFY 2013, of which 54.2 percent were children in low-income families; 19.5 percent were individuals with disabilities; 19.4 percent were low-income adults; and 7.0 percent were elderly. (Virginia has strict Medicaid income eligibility criteria for adults without a child or a disability: 80 percent of the Federal Poverty Level.) For Virginians with disabilities, Medicaid provides access to specialized health care and supports that maintain good health and functional abilities as well as enable participation in their communities.

Medicaid is the second largest expenditure in Virginia's budget, totaling \$7.6 billion in SFY 2013. Growth in both Medicaid enrollment and expenditures in recent years is, to a large degree, a result of both the Great Recession (during which Virginians lost jobs, income and private health insurance) and the slow economic recovery. However, an important reality is that **enrollees who have a disability accounted for 48 percent of Medicaid expenditures in SFY 2013**; and the elderly accounted for 17 percent of the total. Together, these two populations accounted for 65 percent of all expenditures that year. By comparison, low-income adults accounted for only 11 percent of expenditures year; and children, only 23 percent.

Dialogues about rising Medicaid costs must include consideration of **future cost avoidance**. Through Medicaid, individuals with disabilities are able to access services and supports that have multiple benefits beyond good health, including help to maintain or improve functional abilities as well as enable life in their communities rather than in expensive, segregated institutions. Moreover, according to a 2013 US Census report, between 2008 and 2012, the number of adults (under age 65) in Virginia who were *uninsured* increased from 13.1 to 14.3 percent. A 2013 report to the Joint Commission on Health Care noted that over 1 million Virginians were uninsured that year. Without Medicaid, even more people would be uninsured. Without any health insurance, low-income individuals are likely to defer medical care until the condition worsens, leading to more emergency room use and more expensive treatment. In turn, to cover unreimbursed indigent care, hospitals raise their fees for other patients and insurers.

Since 2011, a number of initiatives have been underway as a result of legislative concerns and of federal reform for Medicaid. The General Assembly consistently has directed the state Department of Medical Assistance Services (DMAS) to expand managed care for Medicaid enrollees. As directed by the legislature, DMAS has begun the following initiatives:

- Developed and began regional phase-in of a care coordination model, resulting from the successful application for a federal Financial Alignment Model Demonstration Grant for

Medicare/Medicaid Enrollees (those who are dually eligible). Virginia's program, called **Commonwealth Coordinated Care (CCC)**, is based on person-centered principles, and is designed to (a) improve care coordination, (b) improve timely access to care, (c) promote wellness and independent living, (d) improve service quality, and (e) reduce expenditures. Administered by DMAS, CCC provides care coordination through contracts with several managed care organizations to adult or elderly "dual eligibles" who also meet program eligibility criteria. At present, individuals receiving supports through the Medicaid ID and DD Waivers are not included in CCC.

- Implemented a coordinated care model of behavioral health services covered by Medicaid but not currently under managed care. In May of 2013, DMAS contracted with Magellan Health Services to serve as a **Behavioral Health Services Administrator** for Medicaid enrollees.
- Began developing a blueprint for expansion of a **care coordinated model for all Medicaid enrollees needing behavioral health services**. This is being done in collaboration with Community Service Boards (CSBs) and other stakeholders.
- Expanding **managed care on a regional basis for youth in foster care and in adoption assistance programs** statewide. DMAS is partnering with state and local Departments of Social Services, health insurance plans, and foster/adoptive parents. Expansion will be completed in June of 2014.

The 2013 legislature established the **Medicaid Innovation and Reform Commission (MIRC)**, which began operations that year. MIRC, comprised of General Assembly members, was established to recommend, review, and approve innovation and reform proposals regarding all Medicaid programs. Included in its work have been eligibility criteria, benefit design, service delivery, quality outcomes, payment reform, and cost containment. MIRC additionally reviewed successful Medicaid reform initiatives and private health insurance coverage for uninsured, low-income adults in other states.

An important study on the **impact of Medicaid reimbursement policies for community health care** providers was conducted and completed by the Joint Legislative Audit and Review Committee (JLARC). Its report (*Senate Document #8, 2013*) noted that Medicaid rates for health care have been relatively stable over the past decade, although costs have risen annually, while payment rates by private insurers increased over time. Statewide, JLARC found, Medicaid enrollees had the highest level of access to prescription drugs, acute hospital-based care, and nursing facility care.

Regional variations were found in access to primary care, outpatient hospital care, and hospital-based psychiatric care. Four Planning Districts, all of which are rural and have higher poverty rates, had the lowest access to most health care services: Accomack-Northampton, West Piedmont, Region 2000, and Southside. Significantly, the lowest level of access for Medicaid enrollees statewide was for specialty care, especially outpatient mental health and dental services, because of the lack of participating providers. Less than half of all medical

specialists statewide participate in Medicaid; the lowest participation rate is dentists (only 34 percent). The far Southwest had the lowest access to psychiatrists, other mental health providers, and inpatient psychiatric beds. Excluded from the study were intermediate care facilities for individuals with intellectual disabilities (ICFs/IID) services as well as personal and habilitative care under the **Medicaid Home and Community Based Services (HCBS) Waivers**.

HCBS Waivers play a key role in supporting individuals with intellectual and developmental disabilities in the community. While the General Assembly nearly always provides additional funding for “slots” for the ID Waiver (and in recent years but to a lesser extent, DD Waiver for those with developmental disabilities) the funding is not nearly enough to support those who could benefit from Waiver supports that would enable them to more actively participate in their communities and to contribute to society in meaningful ways.

To meet the requirements of the DOJ Settlement Agreement, the 2011 and subsequent legislatures dramatically increased annual funding of “slots” for the Medicaid Intellectual Disability (ID) and Individual and Family Developmental Disability (DD) Waivers. In State Fiscal Year (SFY) 2014, 735 slots were funded for the ID Waiver; and 130 slots for the DD Waiver. Between SFYs 2010 and 2013, the number of individuals served under the ID Waiver increased from 8,010 to 9,245, an increase of 15.4 percent; under the DD Waiver, the number served increased from 592 to 971 individuals, a 64-percent increase.

Nevertheless, the number of individuals on Medicaid waiver waiting lists continued to grow at an unacceptable rate. At the end of SFY 2013, 6,684 individuals were on the ID Waiver wait list and 1,177 individuals on the DD Waiver wait list. The combined number of individuals on the **ID/DD Waiver wait lists in April 2014 was over 9,000**. Between SFYs 2010 and 2013, the number on the ID Waiver wait list increased by 23.8 percent; those on the DD Waiver wait list increased by 18.5 percent. Further, during the 2014 General Assembly, the Senate determined that the Commonwealth had “overfunded” the ID/DD Waivers based on the requirements of the Settlement Agreement and actually reduced funding for waiver slots. When a budget was passed at the end of June 2014, it included only 15 new DD Waiver slots and 50 new ID Waiver slots for SFY 2015–2016 in addition to those required by the DOJ Settlement Agreement.

In 2013, responsibility for daily operations of the DD Waiver transferred from the Department of Medical Assistance Services (DMAS) to the Department of Behavioral Health and Developmental Services. DBHDS, in collaboration with DMAS, is in the process of **redesigning the ID, DD and Day Support Waivers**. Redesign is intended to address legislative mandates and advocates’ requests for streamlined applications, improved care coordination and service quality, and improved oversight. It additionally will address components of the Settlement Agreement regarding compliance with the Americans with Disabilities Act and the Supreme Court *Olmstead* decision.

The Board supports the current efforts to redesign Virginia’s Home and Community Based Services (HCBS) ID, DD and Day Support Medicaid Waivers. These redesigns must address not

only today's needs but also the needs of a service system that must build increased community capacity and competency in the years to come.

With the recognition that significant work is likely to have been completed before this *Assessment* is published, the Board recommends that **the Commonwealth:**

1. Design waivers that reflect opportunities for increased **individual control of service dollars and budgets**. A state definition for the terms "individual resource allocation" and "individualized budgets" should be adopted as state agencies, providers, individuals with disabilities, and advocates interpret these terms differently. Individualized budgets should not have low, fixed-dollar caps on service plan authorization amounts that do not meet the service and supports needs of recipients.
2. Fund **pilot projects** of the most promising models for individual resource allocation/budgeting to avoid known issues, identify unexpected problems, and the potential for misuse of resources.
3. Allow for increased **consumer direction of services** (within Medicaid regulations), whereby individuals select their own providers and manage caregivers, and not limit consumer-directed services to personal attendant, respite, and companion services.
4. Resolve existing barriers within Virginia's HCBS Medicaid Waivers in a manner that ensures appropriate services and supports are provided to individuals in a **cost-effective** manner. This includes addressing rate disincentives, transportation restrictions, and service limitations.
5. Maintain **choice in case management providers** for all waiver recipients. [The Board does not agree with the Human Services Research Institute (HSRI) recommendation from the waiver study it conducted for Virginia that local Community Services Boards be the sole provider of case management services.] CSBs should be one of many choices that individuals receiving ID/DD Waiver services have. The Board recognizes that work in this area is ongoing.
6. Resolve the significant differences between the wait list systems for the current ID and DD Waivers. A **statewide wait list system** that is fair and equitable for all individuals requiring services should be established. The current definition of "urgent" versus "non-urgent" in the ID Waiver is inadequate. As written, "urgent" criteria do not reflect true emergency status since there are over 3,600 people on the urgent wait list.

In additional areas related to the delivery of long-term care services and supports to individuals with ID/DD, the Board recommends that **the Commonwealth:**

7. Delay plans for the **expansion of coordinated care** to Medicaid enrollees with an intellectual or other disability who receive supports under the ID or DD Waivers as long as needed to ensure thoughtful planning, research, and stakeholder input.

- a. Initiate a process whereby the Departments of Medical Assistance Services (DMAS) and Behavioral Health and Developmental Services (DBHDS) perform due diligence in identifying the **outcomes and challenges** for the ID/DD population that resulted from coordinated/managed care efforts in other states (Kansas as one), and examine the potential impact on capacity and current ID/DD service providers. Barriers identified in other states should be addressed prior to mass enrollment of ID/DD Waiver recipients into coordinated care.
- b. Implement small, regional **pilot programs** to identify and address Virginia-specific barriers.
- c. Make **consumer-directed services and person-centered practices** foundational philosophies for care coordination initiatives.
- d. Analyze **outcomes** of care, including satisfaction outcomes, provided to individuals with ID/DD who were receiving services through the Elderly or Disabled with Consumer Direction (EDCD) Medicaid Waiver and opted in to the Care Coordination Model.

The Board also recommends that the **Department of Medical Assistance Services (DMAS)**:

8. Add comprehensive **dental coverage** for adults under the Medicaid State Plan. If not added as a State Plan service, dental care should be at a minimum added as a service under the new ID/DD Waiver as lack of preventive dental care has been identified as a contributing factor to rising health care costs.
9. Seek funding to develop a **dental demonstration pilot project** that will (a) improve hospital documentation and reporting of emergency room use for dental conditions; (b) either replicate or adapt the Virginia Commonwealth University ER triage model to include counseling and referral to appropriate safety net dental service providers and, when applicable, to the national Healthcare Exchange or Medicaid for insurance coverage; and (c) track changes in ER use for dental care over time. This pilot could not only reduce ER use for dental care but also may reduce health care costs over time as individuals become familiar with and use less expensive community services for dental care.
10. Create and operate a centralized service **call center for complaints** about Medicaid services. Having a call center will provide DMAS with direct and timely feedback from Medicaid enrollees on service delivery problems and performance issues and will enable more responsive corrective actions.

F. Community Living Supports

While Medicaid Waivers are a significant service component for individuals with ID/DD, there are other **community services and supports** available that enable individuals with disabilities to be as independent as possible and to be fully integrated in all facets of

community life. These include services and supports in the areas of: assistive technology (AT) and related services; independent living and related services; Community Rehabilitation Case Management (CRCM) services; non-Medicaid Waiver personal assistance services; and Omnibus Budget Reconciliation Act (OBRA) services. Community supports also include those designed to serve specific disability populations: brain injury services; spinal cord services; (non-Medicaid Waiver) intellectual disability services; services to youth under the Comprehensive Services Act (CSA); interpreter services and related programs for the deaf and hard-of-hearing; and services for the elderly. While the Board has not made recommendations for all programs, they are described in detail in **Volume 2** of this *Assessment*.

As noted above, the Commonwealth has made a major commitment to shift resources from an institutional to a community-based system of care for persons with ID/DD through its **Settlement Agreement with the US Department of Justice**. The Department for Behavioral Health and Developmental Services (DBHDS), which is leading implementation of the Agreement, developed a formal plan to ensure completion of the Agreement's required actions and outcomes and has established a variety of interagency workgroups and internal project teams to ensure implementation. In compliance with the Settlement Agreement, DBHDS has started several new initiatives.

DBHDS developed and implemented a **regional crisis intervention service** for adults (ages 18 or older) with ID and/or DD who also have either a psychiatric condition or challenging behaviors that affect their placement or quality of life. The crisis program model initially adopted was START (Systematic, Therapeutic Assessment, Respite and Treatment), a national evidence-based model. Under START, mobile crisis teams are available 24 hours a day, 7 days a week year-round. The teams also engage the individual and his/her family or caregivers in developing personal crisis intervention and support plans, as well as provide training for implementation of the plan. Other services include short-term therapeutic respite care on either an emergency or planned basis; and psychiatric, behavioral and medication consultation. DBHDS committed to developing START in five regions of the State. However, establishing the regional programs proved challenging, in part due to staff recruitment and retention issues. Although begun in 2011, DBHDS was unable to have crisis mobile teams in operation in all five regions until late fall 2013.

In July of 2013, DBHDS convened a statewide workgroup to evaluate current system capacity to address the needs of both youth and adults with ID/DD who have behavioral or psychiatric crises in order to ensure inclusive communities of care. The workgroups identified service gaps as well as identified both short-term and long-term system enhancements to address those gaps. DBHDS decided that the START model did not provide the flexibility desired by the system and made revisions to the crisis system design. Effective January 6, 2014, DBHDS renamed the program as the **Regional Educational Assessment Crisis Response and Habilitation (REACH)**. The DBHDS planning report, *Developmental Disabilities Crisis Response System: A Road Map to Creating a Community Infrastructure*, provides a broad description of the REACH program and is available online. The points of entry for REACH includes each CSB

emergency services call line and case managers. Development of crisis services for children (a requirement of the DOJ Settlement) has lagged. Best practices for children will be in-home family supports and a crisis plan template, which are in development. Also in development is a short-term “crisis therapeutic home,” for crisis stabilization and linkages to both community providers and the state DD Health Network.

The DOJ Settlement Agreement also required establishment of an **Individual and Family Support Program (IFSP)**, which targets individuals on the ID or DD Medicaid Waiver waiting lists. The purpose is to enable individuals to obtain services and supports that will enable them to remain in their own or family homes and prevent institutionalization. Funded entirely through state appropriations, the IFSP makes available up to \$3,000 per person per year through an application process. In 2013 and 2014, the application process opened in September and closed within 2 months due to the significant demand. Requests were reviewed on a first-come, first-served basis until annual funds were fully committed. Funding criteria were very broad. Because all of the funding was committed virtually immediately, families who had emergent needs were not able to receive the funding until the following cycle. The current process also favors families with the most system knowledge and those who are able to quickly and easily complete the application. During SFY 2013, 825 individuals received IFSP funds; in 2014, 1,293 individuals. DBHDS reports that the most common purposes for which individuals or families used IFSP funds were (1) respite care (including camps), (2) specialized therapies, (3) environmental modifications, and (4) assistive technology.

Although the name of the agency has changed and DBHDS is now administering the Developmental Disabilities (DD) Medicaid Waiver, at present, the agency is limited in its responsibilities and capacity for services to Virginians with **developmental disabilities** other than intellectual disability. By statute, its authority is limited to “development of long-range programs and plans” for developmental services, which are narrowly defined (*Code of Virginia* 37.2-100) as those provided only to individuals with an intellectual disability (ID).

Depending on local funding and priorities, individuals with an ID who are not enrolled in a Medicaid Waiver or who are on a waiting list or are uninsured may be able to access services through their **local Community Services Boards (CSB)**. DBHDS contracts with each of the 40 CSBs statewide (including one behavioral health authority or BHA) to serve as “the single point of entry” into the DBHDS system of care; and it provides “a safety net” of public services (either directly or through contracts). CSBs provide screening, service eligibility, and case management (as the only allowable case management providers for individuals with ID, mental health, or substance abuse disorders). Some CSBs also provide direct services, including residential programs.

For a number of years, the Virginia Board for People with Disabilities has raised concerns about **organizational conflicts of interest** for those CSBs that provide direct services. Some advocates and professionals have voiced similar concerns; others are strong supporters of the current system. With the redesign of the ID/DD Waivers, maintaining choice in case

management services is a key concern for many individuals who receive DD Waiver services. Private providers perform case management under the DD Waiver.

In SFY 2013, there were 20,248 individuals with ID who received **non-Waiver services** through the CSBs; most received case management services. However, **extensive waiting lists** exist for ID services. DBHDS reports that the most frequently identified service needs for those on the ID Waiver waiting list (in SFY 2013, that number was 7,806) were supportive services/day support and case management (especially for youth). The longest wait times (average of 60 or more weeks) were for: residential services (intensive and supervised), employment services, nursing services, assistive technology, personal emergency response systems (PERS), and therapeutic consultation. There are over 1,100 individuals on the DD Waiver waiting list, the administration of which recently transferred from the Department of Medical Assistance Services to DBHDS. CSBs are not presently funded to serve individuals with a developmental disability other than ID.

DBHDS has extensive **administrative responsibilities** regarding behavioral health, substance abuse, and ID services. These include licensing and oversight of all public and private providers of ID services; protection and oversight of human rights; and operational and fiscal oversight as well as quality assurance for both the CSBs and the current five state Training Centers. The DBHDS Office of Licensure (OL) has made positive steps in strengthening **licensure oversight**, with more focus on quality of services, for all public services. The 2012 legislature authorized various sanctions for non-compliance with licensure regulations. Staffing levels for Human Rights and Licensing, however, have not kept pace with the rapid expansion of community providers.

The tragic 2013 death of Gus Deeds, a young man with serious mental illness and the son of state Senator Creigh Deeds, brought intense focus on the scope and quality, not only of crisis intervention services, but also of behavioral health services and supports provided through the CSBs, especially to youth and young adults. As noted by DBHDS crisis data (REACH), a number of youth and adults with ID or DD have either a psychiatric diagnosis or have challenging behaviors that put them at risk of institutional placement. **Timely intervention and treatment** can improve individual functioning as well as reduce family/caregiver stress. In recent years, progress has been made in funding for behavioral intervention services for individuals with ID, but access to both psychiatric and behavioral services remains limited in rural regions or high-poverty areas.

In addition to DBHDS, a resource for specialized services to at-risk youth with serious, chronic psychiatric or behavioral challenges is the **Comprehensive Services Act (CSA)**. CSA goals include (1) early identification and intervention for at-risk youth, (2) strengthening families, and (3) reducing service disparities across localities. The CSA established a single pool of funds comprised of monies from eight funding streams across four state agencies to fund local services to eligible youth. Between SFYs 2007 and 2013, the number of youth served under CSA declined by 20.3 percent; the total served in SFY 2013 was 14,729 youth.

Since 2008, the CSA program has emphasized services to youth in their own communities in order to maintain **natural supports** and to reduce costs. That year, the legislature authorized financial match incentives for that purpose. The State Executive Council for CSA established a hierarchy of service categories with an accompanying incentive rate match system. While controversial at the time, there has been progress; since 2010, the data indicate that residential placements under CSA have decreased over 20 percent. CSA operations are complex, and the program has had many challenges since its establishment.

Each year, the Office of Comprehensive Services develops an annual *Critical Services Gap Survey* regarding available community services, barriers to services, and service gaps at the local and regional levels. Although the top service gap for each CSA region may vary, since SFY 2004, annual surveys have found that **crisis intervention services for youth** are the most important critical service need statewide. Lack of local start-up funds to expand or develop needed critical services has been an ongoing barrier.

In addition to its recommendations regarding Virginia's Home and Community Based Medicaid Waivers—key community supports for persons with ID/DD—the Board makes the following additional recommendations with respect to community-based services and supports. The Board recommends that the **Department of Behavioral Health and Developmental Services (DBHDS)**:

1. Continue to monitor and examine administration of the **Individual and Family Support Program (IFSP)** for individuals with disabilities on the ID or DD Medicaid Waiver wait lists to ensure that future fund awards are used to address needs that will **prevent institutional placement**, strengthen families, and support community living. To further this effort, DBHDS should:
 - a. Ensure that **program information and the application** itself are easily accessible to individuals and families throughout the Commonwealth, including those who do not have computers or case managers to inform them about the availability of funds.
 - b. Develop clearer selection and funding criteria. Although a first-come, first-served basis may still be needed to structure application reviews, it should not be a criteria for selection for an award. **Needs-based priorities** should be identified as criteria based on the IFSP design in the DOJ Settlement Agreement and services covered under the Medicaid Home and Community Based Waivers. Services that are readily available to individuals or families through another source (Medicaid, Medicare, private insurance, etc.) should not be a priority for funding.
 - c. Distribute funds on a **semi-annual or quarterly basis** and establish a “set-aside” amount of IFSP funds for **emergency situations**, for which applications can be made during the year. Clear, objective criteria for “emergency needs” must be developed and implemented.

- d. Designate a **team of conflict-free individuals** to review and prioritize awards based on the new criteria.
2. Work with other relevant agencies of the Commonwealth to eliminate the current **organizational conflict-of-interest issues** regarding Community Services Boards (CSBs) that provide both case management and services. Responsibility for providing case management services must be separate from the responsibility of providing direct services and supports, determining individual funding or service levels, and evaluating services and supports. The Board recognizes that there are CSBs that have already addressed this concern and do not provide direct services.
3. Consider adopting the National Council on Disability's (NCD) **core characteristics of conflict-free case management**, which were identified by the Centers for Medicare and Medicaid Services' program guidelines and regulations for long-term care and are as follows:
 - a. Responsibility for providing case management services must be **separate** from responsibility for providing direct services and supports or determining individual funding or service levels.
 - b. Staff who conduct evaluations and assessments or develop individual plans of care cannot be **related by blood or marriage** to the individual or to any of the individual's paid caregivers.

As noted by the NCD and the aforementioned guidelines and regulations, **effective case management** requires up-to-date knowledge of (a) state, regional and local resources that can support an individual with disabilities and (b) a true understanding and commitment to the principles of person-centeredness, community integration, and community inclusion.

To improve services and address **unmet needs of youth at risk** (including those with disabilities who are in foster care or in adoption assistance programs), the Board recommends that key agencies, including (at a minimum) **DBHDS, the Office of Comprehensive Services, the Department of Juvenile Justice, and the Virginia Department of Social Services' Foster Care Division**:

4. Proactively develop and implement a **comprehensive plan** for service referrals and behavioral interventions at earlier stages to prevent hospitalizations, loss of placements, or incarceration. This comprehensive plan should include identification of service gaps, transition issues, improvements to interagency collaboration, funding needs, and infrastructure needs.

The Board further recommends that **DBHDS**:

5. Develop an **integrated, statewide crisis intervention system** that ensures service access regardless of diagnosis(es), type of disability, age, or locality of residence. The Board

supports Governor McAuliffe's recent creation of a taskforce to improve mental health services and crisis intervention. The Board urges that this taskforce include crisis intervention for Virginians with ID/DD and challenging behaviors or anyone with co-occurring disorders to support person-centered policies and practices, reduce complexity, and improve accountability. **Crisis services for children** should be developed and implemented without delay.

6. Revise current licensure regulations to create a distinct set for ID/DD providers. Licensure regulations are currently all encompassing, being a single set of regulations to cover services for very diverse populations: individuals receiving mental health, substance abuse, and/or ID/DD services. Each disability group has a unique array of service values, principles, and intervention models. The regulations should be reorganized to have a set of **core requirements applicable to all** facilities or services for quality assurance, person-centered principles and for individual health and safety (among others). However, there should be **distinct, specific licensure regulations applicable for each disability population**, which include attention to service and quality-of-life outcomes. An example of licensure regulations specific to ID/DD services was implemented in Massachusetts.

The Board recommends that **the General Assembly:**

7. Approve higher funding levels for **Centers for Independent Living (CILs)** that will enable current CILs to expand service capacity and provide for the development of new CILs in under-served or unserved areas of the State.
8. Expand annual appropriations for the **Public Guardian and Conservator Program** to eliminate waiting lists for those who do require guardianship and to improve the use of currently limited mechanisms for supported decision-making.

The Board recommends that **the Supreme Court of Virginia:**

9. Ensure **civil rights protections** of individuals with ID/DD by developing an annual training initiative for lawyers and circuit court judges on **guardianship and conservatorship**, to include (a) appropriate assessment and identification of individual capacities/abilities for various life decisions and (b) the use of supported decision-making options such as limited guardianships, powers of attorney, and other available mechanisms that do not remove an individual's civil rights.

G. Institutional Supports

The impact of the Commonwealth's Settlement Agreement with the US Department of Justice (DOJ) has been a thread throughout this *Assessment*. The DOJ Agreement is historic for Virginia. Its implementation will play a key, long-term role in influencing the changing landscape of disability services and supports across the lifespan. On June 30, 2014, **Southside Virginia**

Training Center closed, and Virginia joined 39 other states that have closed at least one of their large state institutions. Three of the remaining facilities are scheduled to close by 2020. Southeastern Virginia Training Center (SEVTC), a 75-bed facility, will remain open as a “safety net” program.

As lead agency for the Agreement, the Department of Behavioral Health and Developmental Services (DBHDS), in partnership with other state agencies, the Community Service Boards, and community providers, initiated efforts to **expand community residential and service options**. At the time of this publication, all requests for Training Center admission must first be reviewed by the local Community Services Boards for identification of local service alternatives. Judicial certification remains the requirement for a “regular” admission to a Training Center; and if admission is approved, the individual is referred to either Central Virginia Training Center (CVTC) or to Southwestern Virginia Training Center (SWVTC).

Between SFYs 2010 and 2013, **regular admissions decreased** by 75 percent; respite admissions, by 66 percent; and emergency admissions, by 68 percent. Between June 30, 2011 and March 14, 2014, a significant decline in census at the state Training Centers has occurred: a 43-percent decrease (from 1,160 to 661 individuals), a significant accomplishment. Nevertheless, as of March 2014, among the states and District of Columbia, Virginia has the 4th highest number of individuals with intellectual disabilities residing in large institutions (15 beds or more), such as the Training Centers, nursing facilities, non-state-operated ICFs/IID, and congregate group homes. Virginia **ranked 48th** in the number of people served in community-based settings of less than 15 people according to the 2013 *State of the States in Developmental Disabilities*, an annual report jointly published through federal funding by the Universities of Colorado and Illinois in collaboration with the American Association of Intellectual and Developmental Disabilities (AAIDD).

Virginia stands to benefit in many ways from closing its state Training Centers. Doing so is not only the most ethical action to take—family bonds should be supported and individuals with ID/DD have basic and civil human rights to be a part of their communities. Closure also is the fiscally responsible thing to do. Closures **ultimately expand job opportunities** in disability services at localities statewide rather than just at the localities where the Training Centers are currently situated. Further, when an institution closes, **substantial operational and building maintenance costs** are avoided. By state law, the proceeds from the sale of the land and equipment at each Training Center must go into the **Behavioral Health and Developmental Services Trust Fund**. Trust Fund dollars must be used to develop and increase community integration, choice, and service capacity for individuals with ID/DD. However, due to revenue shortfalls, in the budget passed in June of 2014, the General Assembly eliminated \$5.4 million out of the Trust Fund. This depleted all the money emanating from the sale of surplus property at Southeastern Virginia Training Center that had been in the Trust Fund as well as the remaining proceeds from the sale that were to be deposited in the Trust Fund in January of 2015.

In 2014, the General Assembly passed **Senate Bill 627**. Among other provisions, SB 627 requires that DBHDS

convene a workgroup of interested stakeholders, which shall include members of the General Assembly, to consider options for expanding the number of training centers that remain open, in whole or in part, in the Commonwealth.

The Board participates in this group, which has not yet completed its work. While the outcome is unclear, the stated purpose is **antithetical to the Commonwealth's commitment** to fully transition to an efficient and effective community-based system of services. Virginia clearly must address the infrastructure, service, and support barriers that justifiably concern the families and friends of Training Center residents but should not regress towards maintenance or expansion of large institutions.

Of equal concern is that **expansion of other institutional facilities continues**. Between SFYs 2005 and 2010, the number of non-state-operated intermediate care facilities for individuals with intellectual and developmental disabilities (ICFs/IID) increased from 15 to 36 statewide; and the total ICF/IID-capacity increased from 391 beds at the end of SFY 2010, to 452 beds as of April 2013, a 15.6-percent increase. Bed capacity by facility ranged from 4 beds to 92 beds at St. Mary's Home for Disabled Children in Norfolk, the State's largest, non-state-operated ICF/IID). Most of these ICFs/IID have 8 or more beds, which does not meet the best practice of supporting individuals in small settings of 4 or fewer beds. As the Training Centers continue to downsize, more of these ICFs are likely to be opened in localities statewide in large part due to the generous reimbursement structure as compared to reimbursement under the Home and Community Based Services (HCBS) Waivers. The continued proliferation of these institutional settings remains a concern. It is hoped that **redesign of the ID/DD Waivers** will eliminate the incentive for development of ICFs.

The **age of individuals** served in ICFs/IID is important to monitor. Youth ages 1 to 20 accounted for 23 percent of residents in non-state-operated ICFs/IID in SFY 2013, down from 26.9 percent in SFY 2010. Their presence in these facilities means separation from family and community relationships and, too often, a weakening of family bonds over time. These youth are part of the target population included in the DOJ Settlement Agreement. Seventy percent of ICF/IID residents that year were adults between the ages of 21 and 64, which was a 1-percent increase since SFY 2010. Individuals 65 and older represented 6.7 percent of ICF/IID residents as compared to 4.3 percent in SFY 2010. With many transitioning Training Center residents being elderly, it is anticipated that the percentage of aged individuals in non-state-operated ICFs/IID may increase.

Far surpassing the state Training Centers and community ICFs/IID in number and capacity, **279 nursing facilities** with nearly 32,000 beds operated in Virginia during SFY 2013. The number of individuals in nursing facilities has remained stable: 27,660 in SFY 2010 and 27,941 in SFY 2013, according to the Department of Medical Assistance Services (DMAS).

As was found in the Board's 2011 *Assessment*, the Commonwealth still lacks **reliable data** on the number of individuals with ID or DD placed in these facilities. This became evident in comparing various state and national reports (which also rely on counts from different state agencies). The source of this data reporting problem appears to be multi-layered: a lack of "ownership" and prioritization to track nursing facility placements for individuals with ID/DD; lack of inter-agency efforts to develop and use a standard operational definition for DD; different data reporting and collection mechanisms; failure to conduct or to submit Uniform Assessment Instrument (UAI) findings to the Department for Medical Assistance Services; and both inter-and (sometimes) intra-agency silos.

Like those in ICFs/IID, **children in nursing facilities** are a specific focus in the DOJ Settlement Agreement. According to the data that are available, there are 82 children under age 21 being served in nursing facilities. During SFY 2013, 25 children were expected to transition from nursing facilities or other institutional settings, but only 11 did. In his December 2013 report, the DOJ Independent Reviewer noted that those 11 did not leave as a result of the Commonwealth's initiative. The Reviewer deferred a determination on whether the Commonwealth was in compliance with the requirements of the Agreement.

It has been widely reported that there are individuals in nursing facilities throughout the State who do not have the required **Uniform Assessment Instruments (UAI)s** in their files. Both the Virginia Department of Health (VDH) and the Department of Medical Assistance Services (DMAS), the certification entity for nursing facilities, are aware of this issue. The overall strategy for addressing the problem is not yet known. However, the passage of **House Bill 702** by the 2014 General Assembly, which requires the Department of Medical Assistance Services (DMAS) to contract with private providers and other entities to conduct overdue screenings, should help eliminate the current **backlog of screenings** in certain parts of the Commonwealth. At present, it is clear that the Commonwealth is not adequately meeting its obligation to identify individuals with ID/DD who reside in nursing facilities, and that the data that have been provided over the course of many years are unreliable.

Both ICFs/IID and nursing facilities rely on public insurance for funding, primarily Medicaid and to a lesser extent, Medicare. **The cost of serving individuals in institutional settings** also continues to increase dramatically. In 2013, the annual per capita cost of serving an individual in a state Training Center was \$262,246, an increase of 39.8 percent over the per capita cost in SFY 2010 (\$187,479). As the census continues to decline, that cost will continue to increase to an unsustainable level. The cost of serving individuals in non-state-operated ICFs/IID has also risen sharply: in SFY 2010, the per capita cost was \$137,552; in SFY 2013, \$163,028, an increase of 18.5 percent. Because these rates are linked to Training Center rates, the per capita cost of serving individuals in non-state-operated ICFs/IID will continue to increase.

For nursing facilities, the Genworth *2010 Cost of Care Survey* indicated that the 2010 median per capita cost for services in Virginia ranged from \$65,700 to \$73,000 (semi-private vs.

private room). The *2013 Cost of Care Survey* reports a cost of \$74,469 for a semi-private room and \$83,950 for a private room, an increase of over 15 percent for each.

In an ongoing effort to shift the balance of the service system to community-based services, Virginia received \$28 million in federal funds beginning in 2007 for the **Money Follows the Person (MFP) demonstration project**, now called “the MFP Program.” The plan was to transition 1,041 individuals (of whom 358 must have an ID or DD) from nursing facilities and other institutions to the community in placement settings with 4 or fewer beds (non ICFs/IID) between 2009 and 2011. Similar to other states, Virginia had a very slow start-up for MFP; and between 2008 and 2013, only 539 transitions occurred. Of these, 329 individuals transitioned under the ID Waiver and 7 under the DD Waiver. MFP, now extended until 2016, has not met expectations. Barriers have included **facility resistance** to outreach by transition coordinators, **lack of housing options**, and the **inability to secure environmental modifications or needed technology prior to transition**.

This barrier to transition—*Medicaid waivers cannot pay for the technology or modifications until the individual has been released from the institution; yet, the person cannot leave without these accommodations*—persists. Despite a number of interagency attempts to address the issue, there is still no resolution for individuals who are waiting for placement. The pace of transitions did increase in 2013, and it is hoped this trend will continue as a result of the DOJ Settlement Agreement and effective resolution of barriers.

Regarding institutional services, the Board recommends that **the Governor and General Assembly**:

1. Eliminate the dual system of services by continuing to support and implementing the **closure of three of the four remaining state Training Centers** in a well-planned way that ensures appropriate community infrastructure and services. The closures will facilitate the provision of **quality, community-based alternatives** that will sustain and support individuals with ID/DD in the most integrated settings appropriate to their needs.
2. Develop a strategy to **eliminate the institutionalization of individuals under the age of 21** and task the Department of Medical Assistance Services (DMAS) and the Department of Behavioral Health and Developmental Services (DBHDS) with the responsibility to develop processes that ensure adequate services are provided to these youth and their families.
3. Pass legislation to require a **Certificate of Public Need (COPN)** for both the development of **new ICFs/IID** of more than 6 beds or for **expansion** of a current ICF/IID location by more than 6 beds. Current regulations only require a COPN if a new ICF/IID or an expansion is over 12 beds. New regulation should require ICF/IID developers to demonstrate that (a) an ICF is the only way to meet the needs of individuals with disabilities in their communities, (a) the ICF is the most integrated setting appropriate

for those individuals, and (c) its operations will enable individuals to fully participate in their communities.

4. Closely monitor the rapidly rising costs of services through non-state-operated ICFs/IID and **discourage the use of the ICF/IID model** while consistently promoting more integrated, independent living settings, consistent with the Settlement Agreement. If feasible, re-examine the formula or methods by which **allowed costs** are determined.

As state agencies that fund, license, or monitor non-state-operated institutions, including group (waiver) homes, intermediate care facilities for individuals with intellectual disabilities (ICFs/IID), assisted living facilities, and nursing facilities, the Board recommends that the **Virginia Departments of Health, Aging and Rehabilitative Services, and Behavioral Health and Developmental Services:**

5. Partner in an ongoing initiative to develop and implement a common method and operational definitions by which to **identify and track** individuals residing in or admitted to institutions and to analyze admission trends and factors leading to admission.

The Board further recommends that state disability agencies, including the **Departments for Medical Assistance, Aging and Rehabilitative Services, and Behavioral Health and Developmental Services:**

6. Eliminate **barriers to transitioning from institutions** to the community, including those related to access to environmental modifications or assistive technology. Existing caps on those services should be reviewed to determine if they create further barriers to community living. The Board recommends examining how other states have dealt with these barriers, including states that have used Medicaid administrative funding to cover transition costs.

To promote transparency, the Board recommends that the **Virginia Department for Health (VDH) and DBHDS:**

7. Be required to routinely post on their website those **institutions/providers that have provisional and/or revoked licenses** or have had deficiencies in clinical and safety requirements. Both agencies additionally should list the **parent owners** or organizations that operate multiple facilities to enable public comparison of potential trends regarding violations by a particular organization or owner, not just by single facility.

The Board recommends that **DMAS, DBHDS, VDH, and the Department of Social Services (DSS):**

8. Develop and implement an action plan to revise and update the **Uniform Assessment Instrument (UAI)**, which was developed over 20 years ago. Assessments used in Virginia should be consistent with current federal and state policies as well as **person-centered**

principles. There should be required training and regular certification of UAI screeners (at least every 3 years). Procedures should be in place to ensure that UAIs are conducted and submitted to DMAS in a timely fashion. UAI revision should include key stakeholders.

The Board further recommends that the **VDH Office of Licensure and Certification:**

9. Conduct a systemic case review of individuals with ID or DD placed in nursing facilities to ensure that all have a completed, **current Uniform Assessment Instrument (UAI)** in their file. Lack of a UAI creates unnecessary obstacles to appropriate services and supports and causes discharge delays.

The Board recommends that **DMAS, VDH, DARS, DBHDS, Local Contact Agencies (LCA) and Centers for Independent Living (CILs):**

10. Work together to examine how well the **Return to Community Assessment** (Section Q-MDS) is being implemented to identify trends by facility and by parent owner/organizations over time in terms of referrals and transitions from nursing facilities to the community. The following specific issues should be examined:
 - a. the number of individuals identified as expressing an interest in learning more about the community options in Section Q;
 - b. whether individuals expressing that interest were/are being referred to LCAs and other local agencies (CSBs, CILs, and others) to initiate that process;
 - c. the scope, appropriateness and frequency of training on Section Q referral information and expectations for the Money Follows the Person (MFP) program.

In support of recommendation 10 above, the Board also recommends that the **VDH Office of Licensure and Certification:**

- d. provide follow-up and technical assistance, as indicated, to facilities that have had no or few referrals to an LCA to determine the reasons.

The Board further recommends that **DBHDS:**

11. Improve the quality and timeliness of information available to individuals with disabilities (and their families or guardians and providers) who are transitioning from the state Training Centers. Frustrations over problems with transition processes that could have been avoided have been expressed, particularly by providers. **Critical information**, which has been provided slowly, included the status of “**exceptional rates**” and **bridge funding**.

Finally, with noted qualifications, the Board supports the following recommendations made by the **Independent Reviewer (IR) of the US Department of Justice Settlement Agreement:**

12. Personal Support Teams should develop Individual Service Plans (**ISPs**) for **transitioning individuals** that describe all community services and supports available to the individual. Individuals should be provided with a choice of all options, including those that would provide services in the most integrated setting.
13. ISPs should be **skill-based**. Many individuals with ID, DD or other disabilities need assistance to develop the independent living, social, employment, or other skills necessary to ensure maximum success in the community. However, the Board recognizes that some individuals may not need or want additional skills training and may simply want to live lives that are meaningful to them. ISPs should **include personal choice** regarding the type and level, if any, of skill development to be implemented.
14. **Discharge plans** for Training Center and other institutions' residents should focus first on what the **individual wishes** to do in the community, including participation in employment and/or integrated day activity programs. Community placements should be sought that will enable the individual to achieve those preferences. However, the Board also believes that additional training of Center and community staff in **person-centered practices** may be warranted to improve ISPs and personal outcomes.

Finally, the Commonwealth should be attentive to and prevent the potential unintended consequences of moving people from large institutions to smaller institutions, whether non-state-operated ICFs/IID or nursing facilities. During the closure process, individuals, families, and guardians must be well informed about community options and standards for quality of care must be maintained.

H. Community Housing

Access to suitable, safe, **affordable and accessible housing** is the foundation of inclusive communities. In Virginia and nationally, individuals with disabilities receiving Supplemental Security Income (SSI) benefits or whose income is otherwise limited, continue to be priced out of the housing market. Based on federal guidelines, a SSI recipient receiving \$710 per month (the unreduced benefit amount in Virginia for 2013) could afford monthly rent of no more than \$213 at 30 percent of that monthly SSI benefit. That amount is well below the Average Fair Market Rent of over \$800 per month for a one-bedroom unit.

The importance of addressing the lack of community housing options for people with disabilities was made prominent in a report submitted by the Housing Policy Work Group and Advisory Committee in response to then Governor McDonnell's **Executive Order No. 10**, which required the development of a Housing Policy Framework comprehensive policy that aligned priorities, goals, and resources strategically in a coordinated manner. Noting the mandate for state community integration strategies in the *Olmstead* decision, the report, ***Housing Policy Framework for the Commonwealth of Virginia: Interim Report to the Governor***, points out that Virginia has a

growing need to reduce institutionalization and provide more integrated community housing alternatives for special needs populations.

The report highlighted the common **barriers to community housing** for individuals with disabilities: affordability, accessibility, and coordination of services.

As part of the Commonwealth's 2012 Settlement Agreement with the US Department of Justice, Virginia developed the ***Plan to Increase Independent Living Options***. A cornerstone principle of this plan is the de-coupling of housing and services, meaning that service provision and housing decisions are separate and distinct, and that individuals have choices about where they live and where they may obtain services. The plan includes **five goals** to improve access and choice for individuals with intellectual and developmental disabilities:

1. Expand the inventory of affordable accessible units,
2. Increase access to rental subsidies,
3. Build understanding and awareness of informed choices among individuals with DD, families, public and private organizations, developers, and case managers,
4. Review potential federal and state policy changes that will facilitate increased access and availability to services and supports that permit individuals to choose more independent living options, and
5. Assess and advance coordinated plan implementation.

Following numerous interagency meetings with a variety of stakeholders, including the Board, in 2013, a plan was developed and submitted to the Independent Reviewer for the DOJ Settlement Agreement. The *Plan to Increase Independent Living Options*, although a start, lacked specific numerical targets to meet goal #1 (above). A pilot program, **Rental Choice Virginia**, has been developed to help meet goal #2. However, progress on that and other components of the plan has been slow. At the time of this assessment, the Commonwealth was in the process of responding to a US Housing and Urban Development (HUD) **Notice of Funding Availability (NOFA)** for expansion of integrated, independent housing for persons with disabilities. If selected for an award, Virginia would be able to meet its goals more quickly.

Affordable housing advocates have pushed for the development of a state-funded Housing Trust Fund for many years. Virginia's biennium budget for fiscal years 2013 and 2014 allocated \$7 million dollars in the second year to create the **Virginia Housing Trust Fund**. At least 80 percent of the Fund is to be used for loans to reduce the cost of homeownership and rental housing. Up to 20 percent of the Fund may be used to provide grants for targeted efforts to reduce homelessness. The *Virginia Housing Trust Fund Structure and Use Plan*, (released in November of 2012 prior to funding availability) states:

An important subset of the lower-income population—persons with disabilities—faces even greater difficulty in obtaining appropriate, affordable housing options.

In examining this challenge, the trust fund plan states that the mismatch between the cost of housing and available income

represents a problem for the current recipients of SSI support. It is also a potentially serious impediment to the State's efforts to lower its reliance on institutional settings for persons with a variety of mental, intellectual, sensory or physically limiting conditions. The provisions of the State's recent settlement with the Department of Justice with respect to persons with intellectual disabilities underscored the importance of having appropriate housing resources available for this population.

Beyond affordability is a lack of **accessible housing options** for individuals with disabilities. An ongoing lack of awareness exists among builders, inspectors, landlords, and realtors about the Fair Housing Act and the Americans with Disabilities Act as well as the general principles of **Universal Design** and accessibility. According to HUD's 2011 *Annual Report on Fair Housing*, in FY 2011, for the sixth consecutive year, disability was the most common basis for housing discrimination complaints filed with HUD and Fair Housing Assistance Programs. In some localities, neighborhood resistance to the development of housing options for people with disabilities exists, in large part caused by misconceptions and stereotypes. Data verify the need for increased outreach and education to raise awareness and understanding among key, local stakeholders.

The income barriers identified above and a lack of comprehensive allocation and coordination of resources on the federal, state, and local levels have perpetuated a long-standing **disconnect between housing and disability services agencies**. In order to realize tangible outcomes of improved community living opportunities and choices for people with disabilities, coordinated local planning for housing, transportation, employment, and land use is critical. In Virginia, coordinated efforts to bridge this disconnect are underway. However, the necessary political will, the existence of concrete and actionable steps with accountability, and the allocation and alignment of resources are not evident.

To expand the availability of affordable, accessible housing options for Virginians with disabilities, the Board recommends that the **Health and Human Resources Secretariat**:

1. Enhance and sustain cross-Secretariat collaboration to implement Virginia's **Housing Plan to Increase Community Living Options** developed in response to the Commonwealth's Settlement Agreement with the US Department of Justice (DOJ).
2. Develop a mechanism that targets state and federal housing funds to address critical funding gaps to (a) make **private capital investment** for the expansion of affordable housing feasible and (b) provide a **state rental subsidy** for Virginians with disabilities who choose to live in the community in their own home/apartment with rights of tenancy.

The Board recommends that the **Virginia Housing Development Authority (VHDA) and other public housing agencies (PHAs)**:

3. Adopt and implement a **Housing Choice Voucher program** for DOJ Settlement Agreement target populations. Federal approval has already been provided to VHDA to do just that.

The Board recommends that the **HHR Secretariat, in collaboration with the Commerce and Trade Secretariat**:

4. Develop and implement **statewide education and outreach strategies** to inform builders, developers, realtors, housing counselors, elected officials and community organizations about the Fair Housing Act and the need to increase capacity for the meaningful choice of integrated community living by individuals with disabilities.

The Board recommends that the **Department of Professional and Occupational Regulations within the state Office of Fair Housing**:

5. Rigorously enforce **compliance with the Fair Housing Act** and related laws.

The Board further recommends that the **HHR Secretariat agencies**:

6. Continue to explore and to increase opportunities for choice in housing options available to **Auxiliary Grant (AG) recipients**. Active engagement with the Social Security Administration regarding the expansion of choice in the SSI supplement program should be a priority. This state SSI supplement program is restrictive and needlessly segregates people.

I. Transportation

Transportation issues continue to be one of the most frequently cited barriers to full **community inclusion** by people with disabilities. Reliable transportation is essential to maintain employment, receive medical and other health services, obtain food and clothing, and participate in recreational or civic activities. With the slow economic recovery, local fiscal resources are strained; it is increasingly difficult for localities to provide stable, adequate annual appropriations for public transportation. Localities have an opportunity to bring in federal monies to support **transportation coordination efforts** but have not been consistent in planning for the match funds needed to bring in the federal dollars.

Virginians with disabilities continue to express complaints and concerns to the Board regarding the quality of both **paratransit services and Medicaid-funded human services transportation**. One particular reported problem is the lack of reliability with both types of transportation services—transport is late or does not show up. The true scope of this problem is not clear. Complaint data maintained by the Department of Medical Assistance Services

(DMAS) for Medicaid human services transportation indicate that less than one percent of all rides have complaints, although a sizeable proportion of complaints are for transport that is “no show” or late.

According to DMAS, during SFY 2013, there were 4,176,261 Medicaid non-emergency transportation trips and 50,000 unique riders. For those trips, DMAS reports receiving a total of 28,640 complaints, of which: 24,373 were “provider late”; 2,652 were “provider no-show”; and 1,615, were identified as “other.” Unfortunately, DMAS has neither the staff nor the data system resources for **meaningful performance analysis** such as identifying patterns (i.e., problem providers).

In 2013, a national research organization, Great Blue Research, Inc., conducted a **Client Satisfaction Study** on behalf of **LogistiCare**, the State’s current Medicaid transportation broker. Using a random sample generated by LogistiCare of Medicaid-funded transportation clients living in Virginia at the time, 402 interviews were conducted between December 7 and 22 of that year. The study report, which is not available online, included six areas for investigation. Those, along with the average ratings from the survey, are as follows.

- Call Center Satisfaction: 96.1 percent average positive rating
- Ride Assist Satisfaction: 85.5 percent average positive rating
- Driver Assessment: 93 percent average positive rating
- Vehicle Assessment: 98.1 percent average positive rating
- Service Assessment: 92 percent average positive rating
- Needs Met: 88.8 percent needs met “always” or “most of the time”

All survey respondents reported that they had traveled recently to a Medicaid covered appointment and utilized LogistiCare services. Each respondent was asked a series of questions in each area of investigation and was asked to rank satisfaction on a scale of 1 to 4 where “1” represented “very good” and “4” represented “very poor.” Looking at the results above from a different perspective, more than 11 percent did *not* feel that their transportation needs were met most or all of the time; and almost 15 percent did *not* feel satisfied or very satisfied with the brokerage transportation system.

The LogistiCare Client Satisfaction Study, however, appears inadequately designed to determine areas of service deficiencies and needed improvements. In general, there seems to be a substantial disconnect between DMAS complaint data, LogistiCare’s survey data, and what is heard on a fairly regular basis from service users and their families regarding the dependability and quality of Medicaid non-emergency transportation services.

During the 2014 session of the state General Assembly, HJ 40 was introduced, which (if passed) would have directed the Joint Legislative Audit and Review Commission (JLARC)

to review the Commonwealth's contract with LogistiCare for Medicaid-funded transportation services, identify remedies and alternatives available to the Commonwealth to resolve the issues surrounding LogistiCare's questionable performance, and review the Department of Medical Assistance Services' oversight of the Commonwealth's contract with LogistiCare.

HJ 40 required that JLARC report its findings no later than the first day of the 2015 Regular Session. The resolution further provided that the Commonwealth's contract with LogistiCare not be renewed or extended prior to the completion of this study. The legislature did not pass this resolution. The Board, which supported the study, believes that the proposed JLARC report would have resulted in improved service quality, outcomes, and efficiency.

An important priority for the Commonwealth for the past five years has been the **coordination of human service transportation**. The US Government Accountability Office (GAO) reported in 2013 that people in need of transportation often benefit from greater and higher quality services when transportation providers coordinate their operations. (See *Transportation Disadvantaged Populations, Coordination Efforts Underway, but Challenges Remain, Statement for the Record*, released on November 6, 2013). The GAO identified the lack of federal guidance on how to share costs across programs as a key barrier to increased coordination efforts. The GAO further stated

limited financial resources and growing unmet needs are also challenges for state and local providers and their ongoing coordination efforts—both now and in the future. State and local officials nationally express concern about their ability to adequately address expected growth in elderly, disabled, low-income, and rural populations.

Public transportation, and in particular paratransit services, are heavily subsidized. The GAO estimates that the cost of ADA paratransit services can be 3.5 times more expensive than the average cost of fixed-route trips. This increased expense creates a dilemma: as the need for and use of paratransit service grows, the costs and need for increased funding to subsidize the service expand. The Virginia Department of Rail and Public Transportation (DRPT) has been working closely with localities to develop Coordinated Human Services and Public Transportation Planning Models. While significant gains have been achieved in these efforts, continued planning and implementation of coordination strategies are needed.

To increase the availability and reliability of transportation for individuals with disabilities statewide, the Board recommends that the **Department of Medical Assistance Services (DMAS)**:

1. Develop and implement more rigorous service **quality and satisfaction metrics** to better measure service quality response times, and utilization trends for non-emergency Medicaid transportation services. (Trust, but verify.) The current broker's (LogistiCare)

Client Satisfaction Study is inadequately designed to determine areas of needed improvement or service deficiencies; its findings are dramatically different from the number and frequency of complaints received by advocacy agencies.

Given the critical importance of Medicaid funded non-emergency transportation for Virginians with disabilities and those who are elderly, the Board recommends that **the General Assembly:**

2. Reconsider **authorization of a Joint Legislative and Audit and Review Commission (JLARC) study** similar to HJ 40, which failed in the 2014 General Assembly, to examine program effectiveness and areas for improvement in the 2015 session. In the alternative, the Board recommends that the Administration contract out for a similar study to be conducted.

The Board further recommends that **the Commonwealth:**

3. Provide **incentives for localities to designate matching funds** for federal transportation dollars on a sustainable, long-term basis. The cost to a locality/region to sustain public and paratransit is significant. Para-transit services in particular are highly subsidized. When user demand increases, so does the cost to the locality, which can be a disincentive to expand service.
4. Promote and provide incentives that facilitate **coordinated community development** linking housing, transportation and services. Coordinated planning activities in localities or regions have improved, but continued vigilance is needed.

Finally, the Board recommends that both the **Medicaid Transportation Advisory Committee (MTAC) and the State Agencies Coordinating Transportation workgroup (SACT)**, led by the **Department of Rail and Public Transportation:**

5. Re-establish regular meetings and **communication**. Doing so will promote identification of emerging issues as well as development of systemic strategies to increase/improve transportation services.

III. Conclusions

There have been significant changes in the services and supports available to individuals with intellectual and developmental disabilities across the lifespan. Many improvements have been made, but the Commonwealth is still faltering in numerous areas and does not, in reality, have a disability services “system.”

With respect to the Commonwealth’s historical institutional bias, the Settlement Agreement with the US Department of Justice has been a “game changer.” Virginia’s

policymakers have turned the corner in their efforts to ensure that individuals with intellectual and developmental disabilities are fully included in their communities rather than segregated from society. These efforts are crucial, not only for those leaving institutions but also for those at risk of being institutionalized and for the thousands currently living in the community who are waiting for the supports that will enable them to live as independently as possible—where they choose, with whom they choose—and to engage in the education, work, civic, and social activities that they choose.

Complacency is not an option. There is substantial work to do over the next decade. The Governor and the legislature must provide the leadership essential to achieving real systems change in all of the areas included in this *Assessment* and many more. Policies and programs that will be sustainable over the long term must be designed, and the financial and human resources needed to support a true “system” must be provided.

The Virginia Board for People with Disabilities appreciates the opportunity to provide its *Key Findings and Recommendations* as part of its state and federal mandates to conduct this assessment. Consistent with the Board’s *Benchmarks* for front-loaded, person-centered, and community-based services and supports, the Board hopes that when proposing or passing any policy, regulation, law, or funding, all parties make a conscious effort to ask themselves and each other whether the proposed action:

- ✓ provides equality of opportunity and universal access;
- ✓ cultivates increased self-sufficiency and independence;
- ✓ promotes choice, personal decision-making, and individual responsibility;
- ✓ fosters full and meaningful participation in community life;
- ✓ is non-discriminatory and fully inclusive; and
- ✓ is an investment in the Commonwealth’s future.

