Assessment of Virginia's Disability Services System:

Community Living

Virginia Board for People with Disabilities

2019 Assessment of Disability Services in Virginia Community Living

First edition

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

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The Virginians with Disabilities Act § 51.5-33 directs the Virginia Board for People with Disabilities (VBPD), beginning July 1, 2017, to submit an annual report to the Governor, through the Secretary of Health and Human Resources, that provides an in-depth assessment of at least two major service areas for people with disabilities in the Commonwealth. In June 2018, the Board selected Early Intervention and Community Living as the areas to be covered in the 2019 Assessments. The Board, as part of its authority and responsibility as a Developmental Disabilities (DD) Council under the federal Developmental Disabilities and Bill of Rights Act (42 U.S.C.§15021-15029), is also required to complete a similar analysis as it develops and amends its federal State Plan goals and objectives.

The Assessments on Early Intervention and Community Living, respectively, are not intended to be a comprehensive inventory of all of the services and supports available to individuals with disabilities in the Commonwealth and should not be relied upon as such. Rather, in this Assessment, the Board seeks to identify critical issues, data trends, and unmet needs of people with developmental disabilities, and offer recommendations for improving the delivery of services for people with developmental disabilities in the Commonwealth and the full integration of people with developmental disabilities into all aspects of community life. Although the focus of the analysis and recommendations is on individuals with developmental disabilities, the recommendations would also benefit the broader population of people with disabilities and other populations with similar needs.

The data for this Assessment was obtained from a variety of sources, including state and federal agency websites and reports, legislative studies, and various research publications. We appreciate the assistance of the state agencies that provided information and clarification on the services relevant to their agencies. The policy recommendations contained within this Assessment were developed by an ad hoc committee of the Board and approved by the full Board at its March 13, 2019 meeting.

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Statement of Values

Physical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society, yet many people with physical or mental disabilities have been precluded from doing so because of discrimination …; historically, society has tended to isolate and segregate individuals with disabilities and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem ...

- 42 U.S. Code § 12101 – Americans with Disabilities Act – Findings and Purpose

The Virginia Board for People with Disabilities serves as Virginia's Developmental Disabilities Council. In this capacity, the Board advises the Governor, the Secretary of Health and Human Resources, federal and state legislators, and other constituent groups on issues important to people with disabilities in the Commonwealth. The following assessment of Community Living services and outcomes is intended to serve as a guide for policymakers who are interested in improving Community Living options for people with disabilities in the Commonwealth of Virginia. The Board's work in this area is driven by its vision, values, and the following core beliefs and principles:

Inherent Dignity: All people possess inherent dignity, regardless of gender, race, religion, national origin, or disability status.

Presumed Capacity: All people should be presumed capable of obtaining a level of independence and making informed decisions about their lives.

Self-determination: People with disabilities and their families are experts in their own needs and desires and they must be included in the decision-making processes that affect their lives.

Integration: People with disabilities have a civil right to receive services and supports in the most integrated setting appropriate to their needs and desires, consistent with the Supreme Court's Olmstead decision.

Diversity: Diversity is a core value. All people, including people with disabilities, should be valued for contributing to the diversity of the Commonwealth.

Freedom from Abuse and Neglect: People with disabilities must be protected from abuse and neglect in all settings where services and supports are provided.

Fiscal Responsibility: Fiscally responsible policies are beneficial for the Commonwealth, and they are beneficial for people with disabilities.

Executive Summary

The right of people with developmental and other disabilities to live and participate in the community is well-established in the United States. When the Americans with Disabilities Act (ADA) was passed in 1990, Congress described the isolation and segregation of individuals with disabilities as a serious and pervasive form of discrimination (42 U.S. Code § 12101(a)(2)), and it enacted the ADA to combat this type of discrimination. Today, 29 years after Congress made these statements, people with disabilities continue to face barriers to community living and these rights have yet to be fully realized.

Continuing discrimination, both overt and subtle, prevents many people with disabilities from accessing important community resources, facilities, and services. The persistence of discrimination is reflected in the number of lawsuits regarding the Americans with Disabilities Act, which are increasing each year and totaled 9,373 in 2016 (see Table 1).

Even as people with disabilities continue to face these barriers, their procedural rights to vindication in court are increasingly in question, as states and the United States Congress seek to quell the growing number of legal claims based on the Americans with Disabilities Act. Virginia must protect the rights of people with disabilities to access the courts and vindicate their right to live in and access their communities.

Community Living is about more than just place. Being in the community is an important aspect of Community Living, but equally important is the capacity to be a participatory member of one's community and to exercise control over one's own life to the maximum extent possible. Restrictive guardianship practices, and other policies and practices that presumptively deny people with disabilities the ability to control their own lives, are barriers to full community participation. Thousands of Virginians have been placed under guardianship, some of whom have also had their voting rights revoked (see Table 1). Virginia must work to ensure that state policies and practices facilitate maximum independence and self-determination among people with disabilities.

Many people with developmental disabilities rely upon critical services and supports to live integrated lives in the community and to maximize their independence and self-determination. Long waiting lists and restrictive eligibility criteria limit the ability of many people with developmental disabilities to access these services (see Table 1). Large numbers of people with developmental disabilities currently rely upon the support of aging caregivers to live in the community. Virginia must work to expand access to critical long-term services and supports for people with developmental disabilities, both to meet the existing needs of its citizens with developmental disabilities and to be prepared to accommodate the future needs of those who currently rely upon the support of aging caregivers who will not be able to provide for them indefinitely.

Key Performance Indicator	Latest Data	Year	Trend
Community Access as a Civil Right			
ADA lawsuits in U.S. District Courts	9,373	2016	↑
Employment discrimination complaints, related to disability, filed by Virginians	864	2017	↑ [1]
Employment discrimination complaints related to disability, as a percentage of total employment discrimination complaints, filed by Virginians	32%	2017	↑
Maximizing Independence and Self-Determination			
Virginia's Case for Inclusion state ranking for promoting independence among people with developmental disabilities	38th	2019	↔
Guardianship reports filed with local Department of Social Services (DSS) offices	12,904	2018	↑
Number of Virginians disenfranchised due to a finding of incapacity	518	2018	↑
Access to Critical Services and Supports			
Developmental Disabilities (DD) Waiver waitlist	12,994	June 2018	↑

Table 1: Key indicators of community living for people with disabilities.

[1] While the number of employment discrimination complaints related to disability in Virginia decreased from 921 in 2016 to 864 in 2017, the longer-term trend is an increase.

I. Recommendations Related to Community Access as a Civil Right

The Virginia General Assembly should:

Recommendation 1: Protect civil rights protections of people with disabilities from attempts to weaken the rights of private citizens to enforce their rights in court.

Recommendation 2: Explore models in other states that seek to incentivize proactive compliance with the accessibility requirements of the Americans with Disabilities Act, such as the Certified Accessibility Specialist program in California, for applicability in Virginia, with input from disability advocacy organizations.

The Virginia Board for People with Disabilities and other disability advocacy organizations should:

Recommendation 3: Increase public education efforts around the rights and obligations created by the Americans with Disabilities Act and the Virginians with Disabilities Act.

II. Recommendations Related To Maximizing Independence and Self-Determination

The Virginia Supreme Court, the Department for Aging and Rehabilitative Services (DARS), the Virginia Department of Elections, and the Virginia Board for People with Disabilities should:

Recommendation 1: Collect more data on guardianship in Virginia, including data on the frequency of full versus limited guardianships, and the frequency with which voting rights are preserved.

Recommendation 2: Increase training opportunities for judges, Guardians Ad Litem, guardianship lawyers, and caregivers on supported decision-making as an alternative to guardianship.

The Virginia General Assembly should:

Recommendation 3: Enact legislation to formally recognize supported decision-making as an option in Virginia.

Recommendation 4: Change Virginia law, consistent with the American Bar Association's recommendations, to "explicitly state that the right to vote is retained, except by court order where the following criteria must be met:

(1) The exclusion is based on a determination by a court of competent jurisdiction;
(2) Appropriate due process protections have been afforded;
(3) The court finds that the person cannot communicate, with or without accommodations, a specific desire to participate in the voting process; and
(4) The findings are established by clear and convincing evidence."

The Virginia Department of Behavioral Health and Developmental Services (DBHDS), in collaboration with community partners and disability advocates, should:

Recommendation 5: Improve training of service providers, case managers, and individuals with disabilities on the rights of individuals to have a say in their living situation.

III. Recommendations Related to Access to Critical Services and Supports

The Virginia General Assembly, the Department of Medical Assistance Services (DMAS), and the Department of Behavioral Health and Developmental Services (DBHDS) should:

Recommendation 1: Expand access to personal care assistance by including it as a Medicaid State Plan Benefit in Virginia.

Recommendation 2: Include consumer-directed personal assistance services in the Building Independence waiver.

Recommendation 3: Implement a single Developmental Disabilities (DD) Waiver that combines the three existing waivers (Building Independence, Family and Individual Supports, and Community Living) into a single waiver in 2022.

Recommendation 4: Fund 5,000 DD Waiver slots above and beyond the slots mandated by the Department of Justice (DOJ) settlement agreement by 2021.

Recommendation 5: Collect data on the working conditions of Direct Support Professionals (DSP) in Virginia by joining the National Core Indicators Staff Stability Survey effort, and compare data in Virginia to other states, regions, and localities.

Recommendation 6: Increase Medicaid Waiver services provider wage assumptions made in future rate models in order to attract and retain a qualified Direct Support Professionals (DSP) workforce.

Recommendation 7: Increase skilled nursing rates to at least an amount consistent with the Burns and Associates rate model from March 2016.

Recommendation 8: Convene a consumer-directed services provider workgroup to develop strategies for attracting and retaining qualified consumer-directed services providers, which should include, but not be limited to, individuals and family members of individuals who utilize consumer-directed services.

The Board also endorses the following recommendations of the Provider Issues Resolution workgroup, contained in the 2018 report,* Recommendations to Support a Healthy Developmental Disabilities Provider Network in Virginia*:

Recommendations regarding Direct Support Professional (DSP) workforce:

- Virginia should professionalize the role of the DSP by identifying training requirements that can be made portable across providers to reduce the time and costs associated with bringing qualified DSPs into a new employment setting.

- Virginia should convene a workgroup that explores ways to develop a pipeline for new DSPs that promotes the position as a valid and desirable career choice. Future work should then focus on implementing a tiered credentialing process for DSPs where specialization and advanced training can be pursued.

Recommendations regarding provider rates:

- Virginia should proceed with an immediate rate refresh process that uses Bureau of Labor Statistics 75th percentile data. Except in years that a rebase occurs, DD waiver rates should be refreshed annually going forward to increase providers' ability to recruit and retain qualified staff.

- The Department of Behavioral Health and Developmental Services (DBHDS) should work with the Department of Medical Assistance Services (DMAS) to develop a plan to increase rates in long-term care nursing services across Virginia's waivers.

Background

Community Living is a major focus of federal policy in the United States. The shift from institutions to the community has been well underway in Virginia, as in the rest of the country, for many years. This trend is apparent in state Medicaid expenditure data, which shows that Virginia's investment in Medicaid-funded Home- and Community-Based Services exceeded its investment in Medicaid-funded institutional care just after the turn of the 21st Century (Braddock 2017). It is also apparent in Virginia's state-operated intermediate care facilities for people with intellectual and developmental disabilities (training centers) census trends, which began their decline long before Virginia entered into a Settlement Agreement with the U.S. Department of Justice in 2012, in which it agreed to take steps to accelerate this preexisting trend. Despite these efforts, Virginia still needs to make progress.

Community Living is a difficult concept to define. Community Living isn't just about place; it is also about being an active participant in one's own life and in the life of one's community. Independence and self-determination are essential aspects of being a participatory member of one's community. Self-determination is the ability to make decisions about one's life and to have a say in the services and supports that one needs in order to live a maximally independent and fulfilling life.

Community Living does not look the same for every person. Different people are in need of different services and supports to achieve their greatest degree of independence, self-determination, and community participation. The Board recognizes that some people with developmental disabilities require significant support in order to achieve these goals. The focus of Virginia's policies should be to provide that support, and to do so by the least restrictive means possible.

The Administration on Community Living says the following:

> *All people, regardless of age or disability, should be able to live independently and participate fully in their communities. Every person should have the right to make choices and to control the decisions in and about their lives. This right to self-determination includes decisions about their homes and work, as well as all the other daily choices most adults make without a second thought. (https://www.acl.gov/about-community-living).*

Many of the services that people with developmental disabilities rely on in order to live integrated lives in the community are the subjects of other Assessments published by the Board, including employment services, housing assistance, education services, and transportation services. This Assessment will address access to services in a more general way than those Assessments, with a focus on the overarching means for empowering community participation and on the principal funding sources of disability services, rather than on the nuances of each individual service. The 2020 Assessments will focus on Medicaid and healthcare.

I. Community Access as a Civil Right

Established Rights of People with Disabilities

The origins of the legal right of people with disabilities to enjoy equal access to the community date to the passage of the Rehabilitation Act of 1973. Section 504 of the Act states: "No qualified individual with a disability in the United States shall be excluded from, denied the benefits of, or be subjected to discrimination under, any program or activity that either receives federal financial assistance or is conducted by any executive agency or the United States Postal Service."

In 1985, Virginia expanded the civil rights protections afforded to Virginians with disabilities when the General Assembly enacted the Virginians with Disabilities Act. The Virginians with Disabilities Act made the advancement of the rights of people with disabilities to participate in their communities the official policy of the Commonwealth:

> *It is the policy of this Commonwealth to encourage and enable persons with disabilities to participate fully and equally in the social and economic life of the Commonwealth and to engage in remunerative employment. To these ends, the General Assembly directs the Governor; the Virginia Board for People with Disabilities; the Departments of Education, Health, Housing and Community Development, Behavioral Health and Developmental Services, and Social Services; the Departments for Aging and Rehabilitative Services, the Blind and Vision Impaired, and the Deaf and Hard-of-Hearing; and such other agencies as the Governor deems appropriate to provide, in a comprehensive and coordinated manner that makes the best use of available resources, those services necessary to assure equal opportunity to persons with disabilities in the Commonwealth. (Va Code § 51.5-1)*

Subsequently, the Americans with Disabilities Act (ADA) was signed into law in 1990. Congress clearly articulated its intent in passing the ADA within the first lines of the Act:

> *The Congress finds that—(1) physical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society, yet many people with physical or mental disabilities have been precluded from doing so because of discrimination…*

The ADA went on to describe the isolation and segregation of individuals with disabilities as a "form of discrimination" and "pervasive social problem," and explained that discrimination persists in many areas of public life. The Act included a community integration mandate, which required public entities to administer services, programs, and activities in the most integrated setting appropriate to the needs of the individual with a disability. In 1999, the U.S. Supreme Court affirmed the ADA's community integration mandate in Olmstead v. LC. Since then, states across the U.S. have been transforming their systems of care for people with disabilities, sometimes of their own accord, and sometimes in response to legal action by the Department of Justice or by private litigants.

Together, these laws create a powerful impetus for people with disabilities to enjoy equal access to the benefits and resources of Community Living. Despite this strong legal backdrop, however, barriers continue to prevent many people with disabilities from accessing the community. In earlier Assessments, the Board outlined barriers that inhibit the ability of people with developmental and other disabilities to access their communities in the areas of employment, education, housing, and transportation. People with disabilities continue to face discrimination, both overt and subtle, in ways that limit their access to community resources and amenities. Today, as people with disabilities face these continued barriers to community access, they also face growing efforts to limit their ability to enforce their right to community access.

Enforcing Rights of People with Disabilities

There are two avenues by which the rights of people with disabilities may be vindicated under the ADA: the U.S. Department of Justice (DOJ) has authority to enforce the established rights of individuals with disabilities under the ADA through settlement agreements and legal actions; and individuals with disabilities themselves have a private right of action under the ADA to enforce their rights in court. When the ADA was first drafted, there

was a debate about whether the Act ought to provide for a private right of action at all. The business community expressed concerns about the costs of litigation, while disability rights groups supported a private right of action in order to ensure sufficient incentive to comply with the ADA's provisions. The result was something of a compromise: the ADA provides for a private right of action, but remedies are limited in such actions to (i) injunctive relief, in which the business is required to remove the barrier or provide any needed auxiliary aids, and (ii) attorney's fees, where appropriate (Colker 2000). Financial damages, other than the attorney's fees, cannot be awarded.

The DOJ has pursued hundreds of actions under the ADA over the years to protect the rights of people with disabilities to access the community and to receive state-funded services and supports in the most integrated setting appropriate to their needs. One such action included entering a Settlement Agreement with Virginia, which is now in the process of reducing its reliance on institutional care for its citizens with developmental disabilities and enhancing the community services available to these citizens. Since entering the Settlement Agreement, Virginia has closed three of its five Training Centers for people with developmental disabilities, and another is scheduled for closure in June 2020. Between 2011 and August 2018, Virginia reduced the population of its Training Centers by 86 percent, from 1,084 to 152.

As important as the DOJ's enforcement actions are for prompting systemic change, the private right of action provided for under the ADA and other disability rights laws are a critical avenue for individuals with disabilities to vindicate their rights. Available data suggests that there are increasing numbers of private actions being pursued by people with disabilities under the ADA. For example, data suggests that the number of unlawful employment discrimination complaints related to disability discrimination has been increasing in Virginia, both overall and as a portion of total unlawful employment discrimination complaints. The total number of disability-related employment discrimination complaints filed by Virginians increased by 38 percent between 2009 and 2017, from 627 to 864 (see Figure 1). These disability-related complaints also accounted for an increasing portion of overall complaints, rising from 19 percent in 2009 to 32 percent in 2017, due to the increase in disability-related complaints coupled with a decrease in overall complaints.

Private lawsuits alleging ADA Title III violations filed in Federal District Courts have also been increasing in recent years. Title III of the ADA prohibits discrimination against people with disabilities by places of public accommodation, such as restaurants, theaters, schools, day care facilities, recreation facilities and doctors' offices, as well as in commercial facilities, such as factories, warehouses, and office buildings. According to data collected from federal courts, private ADA lawsuits increased by 28 percent from 7,330 in 2015 to 9,373 in 2016, and have more than doubled since 2011. ADA lawsuits accounted for one in every four civil rights lawsuits filed in federal district courts in 2016 (TRAC 2016).

The reasons for the frequency of, and increase in, ADA lawsuits are not entirely clear. There are likely multiple factors contributing to the trend, including increased knowledge among the disability community about their rights and how to enforce them through the courts; accessibility challenges presented by new technologies, such as online business venues and online customer services; and a lack of clarity about the rights and obligations of individuals prescribed by the law.

It is important to acknowledge that one reason for the frequency of ADA lawsuits is the continued existence of ADA violations. Despite the ADA's 29-year tenure, people with disabilities continue to encounter barriers to community integration that stem from, among other things, a lack of awareness about the rights and obligations prescribed by the law. The Virginia Board for People with Disabilities receives fairly frequent questions about the rights of individuals with disabilities who rely upon the assistance of service dogs, for instance. Some of this confusion stems from the interaction of overlapping state and federal laws.

The reason that has received the most attention in the media and in legislatures across the country, however, is the so-called "serial ADA filer." The phrase "serial ADA filer" is intended to describe an individual who files a large number of ADA lawsuits. There have been instances in some states of individual plaintiffs each appearing in many different ADA lawsuits. Some have argued that many of these cases are frivolous, and that the plaintiffs hope merely to press the defendants into

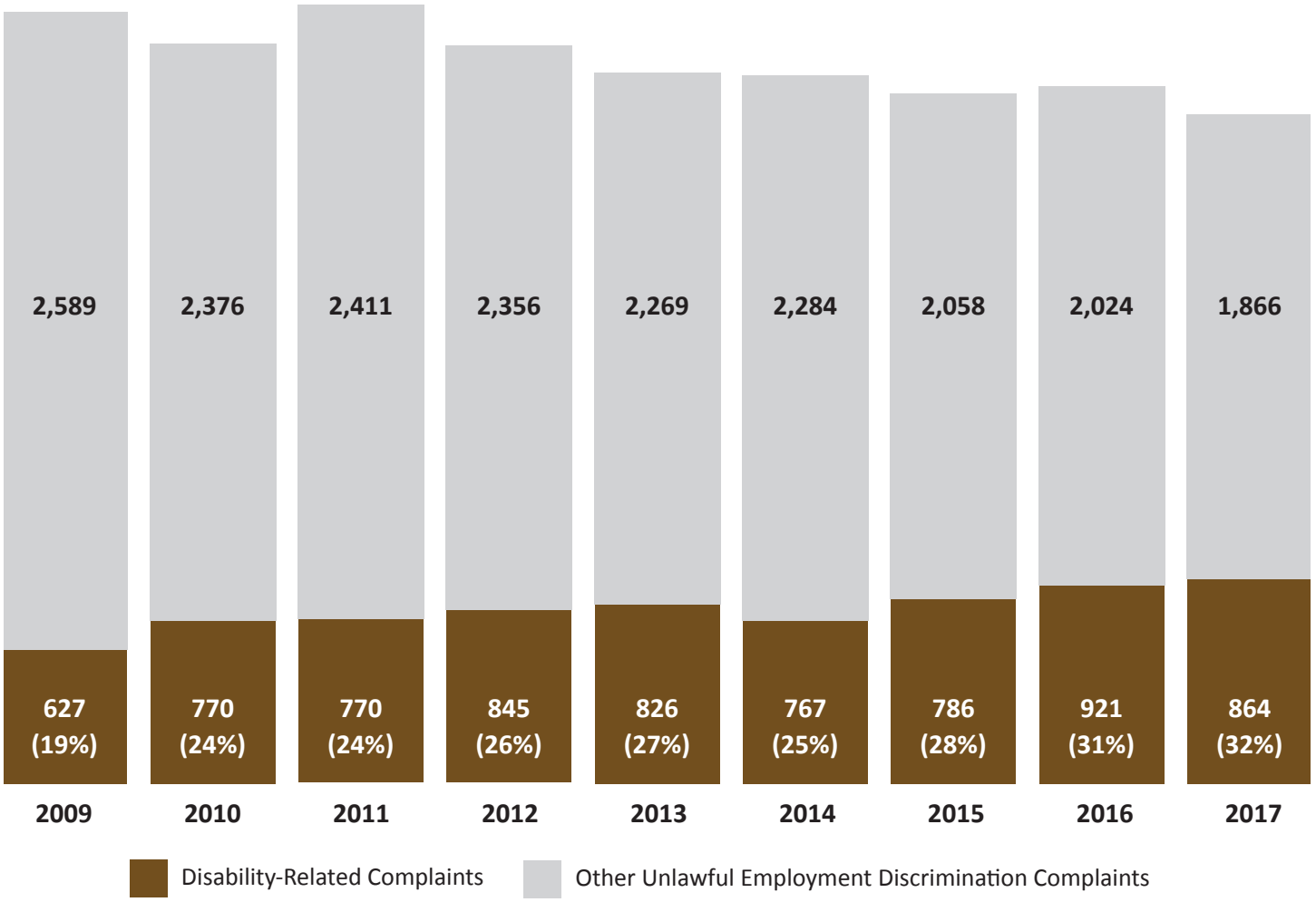

Figure 1: Unlawful employment discrimination complaints filed by Virginians with the Equal Employment Opportunity Commission, 2009-17 (Data obtained from the EEOC website).

a quick settlement agreement rather than to remedy an ADA violation. While these instances have received increased attention of late, they appear to be fairly isolated and mostly limited to specific states, some of which allow for significant damages to be awarded in ADA-related cases. There is little evidence that there is a significant problem of serial ADA lawsuits in Virginia, where significant damages are unlikely.

The rate of ADA-related lawsuits filed in Virginia is significantly below the national average. Of the 9,373 total ADA lawsuits filed in U.S. District Courts in 2016, more than half were filed in just three states (California, Florida, and New York). Less than one percent of all ADA lawsuits filed were filed in Virginia, including 74 in the U.S. District Court for the Eastern District of Virginia, and 15 in the Western District of Virginia. While the rate of ADA lawsuits filed in the United States was 29.1 per million in 2016, the rates in the Eastern and Western Districts of Virginia were 12 and 6.9 per million respectively.

Some states that have experienced large numbers of ADA lawsuits have taken steps to quell the frequency of these lawsuits within their borders. Some of these efforts have involved creating procedural barriers, typically through enactment of Notice and Cure laws. These laws require a potential plaintiff to provide detailed notice of an ADA accessibility violation to an offending party and provide that person or entity a period of time to remove the accessibility barrier prior to seeking relief in court. These efforts are generally opposed by the disability community because the provisions remove existing incentives for entities to proactively comply with ADA accessibility requirements. Notice and Cure laws enable entities to wait to make improvements until they receive notice, without facing any consequences.

Better alternatives to Notice and Cure laws exist and would both protect businesses and incentivize proactive compliance. At least two states (California and Florida) have created programs that provide businesses in the community some limited protection from lawsuits if they hire a state-authorized accessibility specialist to inspect their premises for ADA violations. The entity is then required to fix any violations or put in place a remediation plan to fix violations in a reasonable time period. An entity that takes advantage of this program is granted a conditional defense in the event of future ADA litigation. Unlike a Notice and Cure approach to protecting businesses from ADA lawsuits, these programs incentivize businesses to proactively identify and remedy ADA accessibility violations in order to receive protection against future lawsuits.

Recommendations Related to Community Access as a Civil Right

The Virginia General Assembly should:

Recommendation 1:

Protect civil rights protections of people with disabilities from attempts to weaken the rights of private citizens to enforce their rights in court.

Rationale:

There are repeated efforts to change disability civil rights laws in ways that remove or reduce incentives for public accommodations to proactively comply with existing law. These laws have been in place for over 28 years. Any effort to reduce litigation related to disability civil rights laws should be focused on increasing proactive compliance, and not on shielding violators of the law.

Recommendation 2:

Explore models in other states that seek to incentivize proactive compliance with the accessibility requirements of the Americans with Disabilities Act, such as the Certified Accessibility Specialist program in California, for applicability in Virginia, with input from disability advocacy organizations.

Rationale:

As states seek to address an increase in claims under the Americans with Disabilities Act, some states have explored options to provide protection to public accommodations who take proactive steps to verify their compliance with the ADA and state counterparts. These laws seek to provide some protection to public accommodations, while maintaining incentives for proactive compliance.

The Virginia Board for People with Disabilities and other disability advocacy organizations should:

Recommendation 3:

Increase public education efforts around the rights and obligations created by the Americans with Disabilities Act and the Virginians with Disabilities Act.

Rationale:

Despite the longevity of the ADA and the Virginians with Disabilities Act, there continues to be significant confusion about the rights and obligations created by these laws.

II. Maximizing Independence and Self-Determination

State Performance in Promoting Independence

The Commonwealth has many opportunities to better promote independence among people with disabilities. In its 2019 publication of the *Case for Inclusion*, United Cerebral Palsy (UCP) ranked Virginia 39th among the 50 states and the District of Columbia in how well states serve people with developmental disabilities overall, and 38th for how well states promote independence among people with developmental disabilities. This was a slight improvement over Virginia's ranking in 2016, when Virginia ranked 42nd overall, and 39th in promoting independence.

The overall *Case for Inclusion* rankings are based on a number of factors. Factors include the percentage of the state's fiscal effort that is focused on home- and community-based services versus institutional services; the percentage of individuals who are served in smaller, more homelike settings; the number of people with developmental disabilities who are on waiting lists for critical services; and the percent of individuals who have access to consumer-directed services.

Consumer-directed services promote independence and self-determination by allowing service recipients to hire and direct their own support staff. Studies suggest that people who have the opportunity to use consumer-directed services often express greater satisfaction with their services than people who do not (Kim 2006). In Virginia, consumer-directed services are available for some services under two of the three Medicaid Developmental Disabilities Waivers: the Community Living and the Family and Individual Services Waivers. Surprisingly, the only Developmental Disabilities Waiver that does not offer consumer-directed services, the Building Independence Waiver, is specifically designed for individuals who are living independently with limited supports who could significantly benefit from this service, particularly those with physical developmental disabilities.

Another factor that the UCP bases its state rank on is data from the National Core Indicators (NCI). NCI is one of the only multi-state efforts to gather data related to the personal experiences of people with disabilities through surveys and interviews of individuals with

NCI Questions Regarding Choice and Decision-Making	Virginia	Average Across All Participating States	Percentage Point Difference
Chose or had some help in choosing where they work	94%	86%	8
Uses self-directed supports option	16%	11%	5
Chose or had some input in choosing where they live	57%	53%	4
Decides or has help deciding how to spend free time	92%	91%	1
Chooses or has help choosing what to buy, or has set limits on what to buy with their spending money	87%	86%	1
Chose or had some input in choosing where they go during the day	63%	62%	1
Decides or has help deciding their daily schedule	80%	82%	-2
Can change case manager/service coordinator if wants to	79%	85%	-6
Chose staff or were aware they could request change in staff	58%	64%	-6
Chose or had some input in choosing their housemates or to live alone	28%	41%	-13

Table 2: NCI Data in Virginia Compared to Average of All Participating States (NCI, Adult Consumer Survey 2016-17: Virginia Report).

developmental disabilities and their families. Nearly all states (46 in total, plus the District of Columbia) participate in NCI, allowing for comparisons between them.

The most recent NCI data, from 2016-17, identified certain aspects of self-determination that are worse in Virginia than other states. On about half of the questions regarding the ability of individuals to exercise control over their own services and lives, Virginia fell near the average (defined as within five percentage points) of all participating states (see Table 2). Virginia performed worse than average on the following three questions: "Chose or had some input in choosing their housemates or to live alone;" "Chose staff or were aware they could request change in staff;" and "Can change case manager/service coordinator if wants to." Virginia performed better than average on the question, "Chose or had some help in choosing where they work."

Guardianship and Personal Decision-Making

Some individuals with developmental disabilities require formal or informal supports in order to exercise their maximum level of independence. Guardianship is the most commonly used formal mechanism through which this support is structured. Generally speaking, there are two types of guardianship: full or plenary guardianship, and limited guardianship. In the former, the individual under guardianship loses the right to make the vast majority of decisions about his or her life, including decisions about finances, healthcare, marriage, employment, and voting. In limited guardianship, by contrast, the individual loses the authority to make some of these decisions, but retains the authority to make others. While guardianship, whether full or limited, can be an important tool for protecting the health and safety of people who are deemed incapacitated, it can also substantially limit the individual's personal autonomy and self-determination.

The research has linked self-determination with greater independence, better employment outcomes, and greater community integration, and warns that overreliance on substituted decision-making (guardianship) can hinder desired outcomes. Some scholars have even suggested that the unnecessary use of guardianship can constitute a violation of the integration mandate of the Americans with Disabilities Act (Salzman 2010). Still, guardianship, including full guardianship at times, is entirely appropriate and may be necessary for some people. The challenge is to protect against the overuse of guardianship, and to ensure that its use is limited to what is necessary given the unique circumstances and capacities of the individual.

Guardianship Reports Filed	
2011	6,922
2012	8,403
2013	9,100
2014	9,682
2015	10,356
2016	11,070
2017	12,041
2018	12,904

Table 3: Number of Guardianship Reports Filed in Virginia, 2011-18 (Data from Department for Aging and Rehabilitative Services, Adult Protective Services Division, Annual Reports).

There are a number of ongoing efforts at the state and the national levels to limit the use of guardianship where it is not necessary and to limit the loss of rights when guardianship is necessary. Efforts to formalize supported decision-making as an alternative to guardianship have proliferated in recent years in the United States and internationally. In 2017, Wisconsin became one of a growing number of states to codify supported decision-making agreements. Under this new law, an adult with a functional impairment can enter into a formal agreement with a "supporter," which designates the supporter as a person authorized to assist the individual in making and communicating decisions on matters specified in the agreement without relinquishing the individual of ultimate decision-making

authority (Wisconsin Assembly Bill 655, 2017-18). Other states explicitly reference supported decision-making as a less restrictive alternative to guardianship that a court must consider before ordering guardianship.

There is limited data available on the use of guardianship and its alternatives, such as supported decision-making, but what data is available suggests that the number of people under guardianship in the Commonwealth is increasing. Guardians are required to submit an annual report to their local Department of Social Services office. The number of guardianship reports submitted increased by 86 percent between 2011 and 2018, from 6,922 to 12,904 (see Table 3). This data unfortunately does not include information on the characteristics of the individuals placed under guardianship, such as disability status, nor whether the individual was placed under full versus limited guardianship.

While there is currently very limited data available on guardianship proceedings in Virginia's courts, anecdotal reports from guardianship lawyers and others suggest a lack of consistency in how courts address guardianship issues, including the treatment of voting rights. When a court rules that an individual is incapacitated and in need of a guardian, that individual is considered "mentally incompetent" for the purposes of Art. II of Virginia's Constitution and is therefore ineligible to vote in Virginia unless the court order "specifically provides otherwise" (VA Code § 64.2-2000).

Virginia law provides no guidance to judges for determining when an otherwise incapacitated person retains the capacity to vote. Consequently, different judges may apply different standards, as indicated by anecdotal reports. In 2007, the American Bar Association endorsed a single standard for determining whether an individual retains the capacity to vote: A person under guardianship would retain the right to vote unless "the court finds [by clear and convincing evidence] that the person cannot communicate, with or without accommodations, a specific desire to participate in the voting process" (American Bar Association, House of Delegates 2007).

There is no data available on the percentage of guardianship orders that specifically reserve the right to vote for the individual under guardianship. When the court issues a guardianship order without specifically reserving the individual's right to vote, the clerk of court is required to send a copy of the order to the Virginia Department of Elections. According to data obtained from the Virginia Department of Elections, the Department received an average of approximately 500 such orders annually from 2015 to 2018 (see Table 4). It is not clear how many guardianship orders reserved the right to vote during those same years, however, because there is no data available on the total number of guardianship orders filed in the Commonwealth.

Number Disenfranchised Due to Adjudication of Mental Incapacity by Year	
2015	464
2016	485
2017	521
2018	518

Table 4: Number of Disenfranchised Virginians Due to Adjudication of Mental Incapacity, 2015-18 (Data obtained from the Virginia Department of Elections).

Recommendations Related to Maximizing Independence and Self-Determination

The Virginia Supreme Court, the Virginia Department for Aging and Rehabilitative Services (DARS), the Virginia Department of Elections, and the Virginia Board for People with Disabilities should:

Recommendation 1:

Collect more data on guardianship in Virginia, including data on the frequency of full versus limited guardianships, and the frequency with which voting rights are preserved.

Rationale:

There is very limited data currently available related to guardianship in Virginia. The available data suggests that the number of people under guardianship in Virginia continues to rise. It is unclear what the causes of that increase are, or what the demographic makeup of people under guardianship is. This information is essential for assessing whether Virginia's guardianship laws and practices are effective.

Recommendation 2:

Increase training opportunities for judges, Guardians Ad Litem, guardianship lawyers, and caregivers on supported decision-making as an alternative to guardianship.

Rationale:

Even absent formal codification of supported decision-making in Virginia, supported decision-making remains a viable option for individuals who have the capacity to make decisions, but who may require some accommodations to fully understand complex information or to communicate their preferences.

The Virginia General Assembly should:

Recommendation 3:

Enact legislation to formally recognize supported decision-making as an option in Virginia.

Rationale:

Supported decision-making is increasingly being recognized as an alternative to guardianship that allows an individual to maintain greater independence and self-determination. Several states have codified supported decision-making as a state recognized paradigm. Virginia has not.

Recommendation 4:
Change Virginia law, consistent with the American Bar Association's recommendations, to "explicitly state that the right to vote is retained, except by court order where the following criteria must be met: (1) The exclusion is based on a determination by a court of competent jurisdiction; (2) Appropriate due process protections have been afforded; (3) The court finds that the person cannot communicate, with or without accommodations, a specific desire to participate in the voting process; and (4) The findings are established by clear and convincing evidence."
Rationale:
There is currently no explicit standard in Virginia state law for when an individual under guardianship retains the capacity to vote. This lack of a standard appears to have resulted in inconsistent application of the law. Adopting the American Bar Association endorsed standard would better ensure consistency in judicial application, and it would better ensure that individuals with the capacity to do so retain the right to vote.

The Virginia Department of Behavioral Health and Developmental Services (DBHDS), in collaboration with community partners and disability advocates, should:

Recommendation 5:
Improve training of service providers, case managers, and individuals with disabilities on the rights of individuals to have a say in their living situation.
Rationale:
According to NCI data, Virginians with disabilities who participated in the 2016-17 Adult Consumer Survey were less likely than participants from other states to indicate that they had chosen, or had some input in choosing, their roommate or to live alone.

III. Access to Critical Services and Supports

Many people with developmental disabilities rely upon critical long-term services and supports, often provided by family members or other unpaid caregivers, in order to live integrated lives in the community. An estimated 75 percent of Virginians with intellectual or other developmental disabilities reside with a family caregiver, while only nine percent reside in a supervised residential setting, and the remainder reside alone or with a roommate. Of the 75 percent who reside with a family caregiver, an estimated 23 percent reside with a caregiver who is age 60 or over, suggesting that there is a significant pool of individuals who will be in need of additional state-provided supports in the near future, when their aging caregivers are no longer able to provide the support they need.

For people with developmental disabilities who rely upon state-funded services and supports, there are two overriding issues that affect the availability of critical services and supports: the growing Developmental Disabilities Waiver waitlist, and the growing Direct Support Professional (DSP) workforce crisis. Neither of these issues is especially new, but both are developing increased urgency.

Medicaid Developmental Disabilities Waiver Waitlists

Medicaid is the largest funding source for long-term services and supports for people with developmental disabilities in Virginia and across the country. There are two principal ways in which states fund long-term services and supports through Medicaid: states can fund some limited long-term services and supports through their Medicaid State Plan, or states can provide these services through a Medicaid Waiver program.

One of the key long-term services and supports available through Medicaid is personal care services. Personal care services are services provided by an attendant who helps with daily activities such as, bathing, dressing, and grooming. For individuals who are unable to complete these activities without the assistance of others, personal care services can help enhance their independence and their quality of life. The provision of these services can help maintain an individual's level of functioning and prevent incidents that could result in the individual's need for more intensive services, including institutional level of care. Thirty-three states and the District of Columbia offer personal care services as a Medicaid State Plan benefit. Virginia is not among them. Instead, Virginia offers personal care assistance and other long-term services and supports, such as assistive technology, employment supports, habilitation and group home supports, through 1915(c) Medicaid Waivers. This allows the Commonwealth to use cost containment measures that are not allowed under traditional Medicaid, including narrowly defining the population of individuals who are eligible for the services, and capping the number of individuals who may receive Waiver services. Because Medicaid Waivers are designed to serve as an alternative to institutionalization, only individuals who meet an institutional level of care (Intermediate Care Facility level of care in the case of Virginia's Developmental Disabilities (DD) Waivers), are eligible for these services.

The result of these cost containment measures is the denial of Medicaid-funded personal care assistance and other long-term services and supports to a large number of individuals who would benefit from them. There are typically almost as many people on a waiting list for Waiver services from one of the Commonwealth's three Developmental Disabilities Waivers (the Building Independence Waiver, Family and Individual Supports Waiver, or Community Living Waiver) as there are receiving them. As of June 2018, there were 13,944 individuals with intellectual or other developmental disabilities enrolled in one of the Commonwealth's Developmental Disability Medicaid Waivers, and another 12,994 individuals on a waiting list for one of these Waivers. Some individuals may be eligible for services while awaiting a DD Waiver slot, such as through the Commonwealth Coordinated Care Plus (CCC Plus) Waiver. The CCC Plus Waiver has more stringent eligibility criteria than Developmental Disabilities Waivers. To be eligible for the CCC Plus Waiver, an individual must be 65 years of age or older, or have a disability and medical or nursing needs that put that individual in imminent risk of placement in a nursing facility. Additionally, individuals who are under

the age of 21 may be eligible for personal care services through the Early and Periodic Screening, Diagnostic, and Treatment program if they meet medical necessity criteria for these services. Most adults on the DD Waiver waitlist do not meet the eligibility criteria for the CCC Plus Waiver and those over 21 do not qualify for Early Periodic Screening, Diagnostic, and Treatment services.

Some Waiver services, including Assistive Technology and Electronic Home-Based Supports, are subject to service limitations. There is a $5,000 annual limit on both of these services through a Medicaid Waiver in Virginia. With recent advances in smart home technology and other innovations, the ability for assistive technology to liberate people with disabilities is ever-increasing. A significant upfront investment can reduce the overall service needs of many individuals.

There are some limited options available to individuals who are on a waiting list for one of the Commonwealth's DD Waivers. Individuals who are on the DD Waiver waitlist may be able to access limited assistance through the DBHDS Individual and Family Support Program (IFSP). IFSP provides funding for services and items that allow individuals to continue living in their own homes or the homes of family members. These services and items may include respite, day support, therapeutic activities, home modifications, personal attendant care, medical care, or other similar services and supports. These funds are quite limited, however. The maximum amount of funds that an individual can receive in 2019 is $1,000. The number of individuals who received funds through the IFSP program was 2,943 in 2016, 2,674 in 2017, and 3,210 in 2018.

Provider Capacity and the Disability Workforce Crisis

Even with state funding for long-term services and supports, a lack of providers and workforce challenges limit the ability of some individuals to obtain quality services. This is especially true in some rural regions of the state.

One of the challenges that providers consistently identify as a barrier to expanding their service reach is increasing difficulty attracting and retaining qualified staff to provide services. The demand for Direct Support Professionals (DSP), skilled nursing providers, and other professional supports that allow individuals with disabilities to live in the community is increasing, and is expected to increase for the foreseeable future. Some estimate that as many as a million new direct support positions will need to be filled nationally by 2022 (AAIDD 2016). This increased demand is driven by the aging of the population, the desire to age in place, and the transition from institutional to community-

	FY 2015 Rates*	Burns & Ass.'s Recommended Rates*	FY 2019 Rates*
Skilled Nursing: Registered Nurse	**ROS: $6.42****	**ROS: $14.77**	**ROS: $9.29**
	NOVA: $7.80***	**NOVA: $18.37**	**NOVA: $11.28**
Skilled Nursing: Licensed Practical Nurse	**ROS: $5.57**	**ROS: $11.36**	**ROS: $8.05**
	NOVA: $6.76	**NOVA: $13.71**	**NOVA: $9.78**

Table 5: Skilled Nursing Rates compared: FY 15; Burns & Ass's; and FY 19 rates.

** Rates are calculated based on quarter hour increments.*
***ROS = Rest of State*
****NOVA = Northern Virginia*

based care for the aging and people with disabilities. Not only is the Commonwealth not prepared for this increased demand, but the disability workforce is already in crisis.

The DSP workforce crisis is of national scope, though there is limited systematic data on the scope of the problem in Virginia. There are ongoing efforts to gather better data on the DSP workforce. The largest of such efforts is the National Core Indicators (NCI) Staff Stability Survey, in which 19 states and the District of Columbia participated, but Virginia did not. The most recent survey in 2017 revealed that 35 percent of DSPs employed by survey respondents had been employed for a year or less. The average turnover rate was 44 percent across all participating states and ranged from 24 percent to 69 percent in individual states. Unfortunately, comparable data is not available for Virginia.

While there are likely many reasons driving the DSP workforce crisis, there is a general consensus that low wages, limited or no benefits, and very limited career advancement opportunities are significant drivers. The median hourly wage for a DSP was $12.09 per hour among respondents to the most recent NCI Staff Stability Survey (2017 Staff Stability Survey Report, 2019). DSP wages have been stagnant for years and have actually declined when adjusted for inflation. According to some estimates, nearly half of all DSPs qualify for public assistance, such as medical or housing assistance (President's Committee for People with Intellectual Disabilities 2017).

Most DSP wages are not set directly by the state, but are factored into a state's provider reimbursement rates. Reimbursement rates in Virginia are determined in accordance with provider rate models that make a series of assumptions about provider costs, including the costs of hiring and maintaining a DSP workforce. Virginia's provider rate models incorporate assumptions about the future wages of the DSP workforce that are based, in part, on current wages paid to the workforce. The DSP workforce, however, has been underpaid for many years, a factor which has contributed to low retention rates and high turnover rates. Rate models that base future rates largely on historical wages fail to account for previously unmet needs and changing workforce needs.

A Provider Issues Resolutions Workgroup developed recommendations in 2018 to support a healthy developmental disabilities provider network in Virginia. Several of these recommendations were intended to address the DSP workforce crisis, including the following:

Recommendation 1

Virginia should professionalize the role of the DSP by identifying training requirements that can be made portable across providers to reduce the time and costs associated with bringing qualified DSPs into a new employment setting.

Recommendation 2

Virginia should convene a workgroup that explores ways to develop a pipeline for new DSPs that promotes the position as a valid and desirable career choice. Future work should then focus on implementing a tiered credentialing process for DSPs where specialization and advanced training can be pursued.

Recommendation 3

DBHDS should devise a method of simplified documentation for DSPs that meets expectations for service provision while reducing the time and effort needed to document services and supports.

In addition to DSPs, Virginia's provider reimbursement rates for skilled nursing are very low. A Rate Study published by Burns and Associates in March 2016 recommended increasing skilled nursing rates by more than 100 percent (see Table 5). This increase would have brought them closer to a competitive rate for the profession. This increase was not fully adopted by the General Assembly, however, and skilled nursing rates remain substantially low. For this reason, the Provider Issues Work Group recommended developing a plan to increase long-term nursing reimbursement rates in Virginia's Medicaid program.

DBHDS recently launched a new program to expand access to services in underserved areas called the "Jump-Start Funding" program. It provides startup funds for new and expanding providers of certain home- and community-based services including but not limited to community engagement, employment and community transportation, and in-home supports.

The funding can be used for business licenses/permits, legal fees, staff recruitment incentives, staff training, advertising, software, security systems, and other startup costs.

DBHDS used new mapping technology to pinpoint underserved areas by overlaying provider service areas with waiver recipients. This data allows the Department to target Jump Start funds to the areas where they are most needed. This program is still in its infancy. As of the writing of this Assessment, only one provider had been awarded a startup grant, and it had yet to begin the process of expanding its service reach to an underserved area. Thus, while this program appears to have significant promise, it is too early to know whether it will have the desired effect of expanding access to critical services in underserved areas.

Recommendations Related to Access to Critical Services and Supports

The Virginia General Assembly, the Department of Medical Assistance Services (DMAS), and the Department of Behavioral Health and Developmental Services (DBHDS) should:

Recommendation 1:

Expand access to personal care assistance by including it as a Medicaid State Plan Benefit in Virginia.

Rationale:

Medicaid is the single largest funder of long-term services and supports in Virginia. Too many Virginians do not have access to critical services and supports because of restrictive eligibility requirements and long waiting lists. Including critical services, like personal care assistance, in Virginia's Medicaid State Plan would increase access to them.

Recommendation 2:

Include consumer-directed personal assistance services in the Building Independence waiver.

Rationale:

The Building Independence Waiver is specifically designed for individuals who are capable of living in the community with limited supports, yet paradoxically it is the only one of Virginia's three DD Waivers that does not offer consumer-directed personal assistance.

Recommendation 3:

Implement a single DD Waiver that combines the three existing waivers (Building Independence, Family and Individual Supports, and Community Living) into a single waiver in 2022.

Rationale:

The Board has long advocated for a single DD Waiver. A single waiver would allow individuals to receive services based on their needs, rather than on the slot that they are ultimately awarded. It would also enable families to plan for future needs without having to worry about the ability to move to a different waiver.

Recommendation 4:

Fund 5,000 DD Waiver slots above and beyond the slots mandated by the DOJ settlement agreement by 2021.

Rationale

This would help Virginia significantly reduce the waitlist for critical services and supports through Virginia's DD Medicaid Waivers.

Recommendation 5:

Collect data on the working conditions of Direct Support Professionals (DSP) in Virginia by joining the NCI Staff Stability Survey effort, and compare data in Virginia to other states, regions, and localities.

Rationale

It is widely recognized that there is a DSP workforce crisis in the United States and in Virginia, but there is limited data available to assess the extent to which this crisis is impacting Virginia. The NCI Staff Stability Survey is an attempt to gather some data on this critical issue.

Recommendation 6:

Increase Medicaid Waiver services provider wage assumptions made in future rate models in order to attract and retain a qualified Direct Support Professional (DSP) workforce.

Rationale:

Even in the absence of specific data for Virginia, it is clear that the DSP workforce is affected by low wages and that the demand for DSPs will only increase in the future.

Recommendation 7:

Increase skilled nursing rates to at least an amount consistent with the Burns and Associates rate model from March 2016.

Rationale:

The recommended skilled nursing rates from the March 2016 Burns and Associates rate study were never fully realized. This is a critical disability services area, and the rates that are currently provided are substantially low compared to national and regional data.

Recommendation 8:

Convene a consumer-directed services provider workgroup to develop strategies for attracting and retaining qualified consumer-directed services providers, which should include, but not be limited to, individuals and family members of individuals who utilize consumer-directed services.

Rationale

Virginia has focused significant efforts on developing a competent network of providers to meet the support needs of people with developmental disabilities in the Commonwealth. It has convened provider focused workgroups, and taken a number of other steps to gain insights and recommendations from the agencies who provide these services and supports. Less focus has been placed on developing a community of qualified and competent consumer-directed services providers.

The Board also endorses the following recommendations of the Provider Issues Resolution workgroup, contained in the 2018 report,* Recommendations to Support a Healthy Developmental Disabilities Provider Network in Virginia*:

Recommendations regarding DSP workforce:

- Virginia should professionalize the role of the DSP by identifying training requirements that can be made portable across providers to reduce the time and costs associated with bringing qualified DSPs into a new employment setting.

- Virginia should convene a workgroup that explores ways to develop a pipeline for new DSPs that promotes the position as a valid and desirable career choice. Future work should then focus on implementing a tiered credentialing process for DSPs where specialization and advanced training can be pursued.

Recommendations regarding provider rates:

- Virginia should proceed with an immediate rate refresh process that uses Bureau of Labor Statistics 75th percentile data. Except in years that a rebase occurs, DD waiver rates should be refreshed annually going forward to increase providers' ability to recruit and retain qualified staff.

- The Department of Behavioral Health and Developmental Services (DBHDS) should work with the Department of Medical Assistance Services (DMAS) to develop a plan to increase rates in long-term care nursing services across Virginia's waivers.

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