



**Assessment of
Virginia's Disability
Services System:
Residential Services**

**Day and Employment
Services**



**Virginia Board for
People with Disabilities**



2020 Assessments of Residential Services and Day and Employment Services Available in the DD Waivers

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:

Virginia Board for People with Disabilities

Washington Office Building
1100 Bank Street, 7th Floor
Richmond, VA 23219

804-786-0016
804-846-4464 (Toll-free)
804-786-1118 (Fax)
e-mail: info@vbpd.virginia.gov
www.vaboard.org

Funding for this product was supported, in part, by the Virginia Board for People with Disabilities, under grant number 2101VASCDD-00, from the U.S. Administration for Community Living (ACL), Department of Health and Human Services, Washington, D.C., 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.

The Virginia Board for People with Disabilities would like to thank all of the agencies, organizations, and other individuals who contributed data and information to these Assessments.



VBPD Chair
Matthew Shapiro

VBPD Executive Director
Teri Morgan

Author
Clare Huerta, Deputy Director of Public Policy and Legislative Affairs

Editing
Nia Harrison, Director of Planning, Research and Evaluation
Benjamin Jarvela, Director of Communications
Megan Weems, Communications Assistant

***Special thanks to the members of the Virginia Board
for People with Disabilities Disability Assessment subcommittee***

Alexus Smith • Donna Lockwood • Phil Caldwell
Ed Turner • Frederique Vincent



COMMONWEALTH OF VIRGINIA
Virginia Board for People with Disabilities

Matthew Shapiro
Chair
Frederique Vincent
Vice Chair
Alexandra Dixon
Secretary
Teri Morgan
Executive Director

*Washington Building, Capitol Square
1100 Bank Street, 7th Floor
Richmond, Virginia 23219*

804-786-0016 (TTY/Voice)
1-800-846-4464 (TTY/ Voice)
804-786-1118 (Fax)
info@vbpd.virginia.gov
www.vaboard.org

June 30, 2021

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 September 2020, the Board selected Residential services and Day and Employment Services in the Medicaid Developmental Disabilities Waivers as two areas to be covered in the 2020 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.

In these two Assessments, the Board seeks to determine the extent to which new residential and day services, and opportunities for competitive integrated employment, have furthered the goals of Virginia's 2016 redesign of Medicaid home and community-based services waivers. The Board makes recommendations to increase the availability and utilization of these services, as well as increase individual empowerment in the DD services system.

The data for these Assessments 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 and oversight responsibilities relevant to their agencies. The policy recommendations contained within these Assessments were developed by an ad hoc committee of the Board and approved by the full Board at its June 9, 2021 meeting.

Table of Contents

Statement of Values	i
Executive Summary	ii
Purpose	1
Methodology	1
Background: Transforming Services to Promote Inclusion and Integration	2
Assessment of New Residential Services Available in the DD Waivers	6
Landscape: Options and Trends in Services	6
Opportunities to Expand Supported Living	14
Opportunities to Expand Independent Living Supports	16
Opportunities to Expand Shared Living	17
Opportunities to Expand Assistive Technology, Environmental Modifications, Electronic Home Based Supports, and other Services	19
Opportunities to Empower Individuals	21
Supported Employment and New Day Services available in the DD Waivers	25
Landscape: Options and Trends in Services	25
Opportunities to Expand Supported Employment	32
Opportunities to Supported Integrated Day Services	38
Opportunities to Empower Individuals	41
Appendix A: Focus Groups	42
Appendix B: Family Member Survey	45
Appendix C: Stakeholder Discussion Groups	50
Residential Assessment Works Cited	51
Supported Employment and New Day Services Assessment Works Cited	54

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 Disability 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 assessments of residential, day, and employment services for individuals with intellectual disabilities are intended to serve as a guide for policymakers who are interested in ensuring that people with disabilities live fully integrated lives in their communities, with the supports they need, based on their interests and lifestyle choices. 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, sexual orientation, 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. 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 our neighborhoods and of the Commonwealth.

Freedom from Abuse and Neglect: People with disabilities must be protected from abuse, neglect, and exploitation 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.

PURPOSE OF THE ASSESSMENTS

To determine the extent to which new residential and day services, and opportunities for competitive integrated employment, have furthered the goals of Virginia’s 2016 redesign of Medicaid home and community based services waivers, referred to as the Developmental Disability (DD) waivers.

The goals of the 2016 redesign of the DD waivers were to “better support individuals with intellectual and/or other developmental disabilities to live integrated and engaged lives in their community” and to “offer services that promote community integration and engagement.”

Executive Summary

Data, research, and feedback from people with disabilities and other stakeholders consistently show that the new residential and day services of waiver redesign, as well as opportunities for competitive integrated employment, are fraught with provider capacity issues, individual access and choice issues, and general confusion about the new services and how they operate.

As of September 2020, new residential service authorizations (Independent Living Supports, Supported Living, and Shared Living) still only accounted for about three percent of all residential service authorizations under all DD waivers (Virginia Department of Behavioral Health & Developmental Services, November 2020). Providers have been slow to offer these services and few individuals have benefited from them.

The Commonwealth still lags behind integrated day and employment goals set through the Department of Justice (DOJ) Settlement Agreement. Review of the data and agency reports shows that there are significant gaps in addressing barriers to employment and community engagement, particularly for people with more support needs.

VBPD’s research found that, to work as designed, the new services require strong self-advocacy, tailored approaches appropriate to individual needs, and more providers able to adapt to new ways of delivering supports.

Assessed Residential Services and Supports

Supported living has been an available service in the Community Living and Family and Individual Supports waivers since 2016. Yet, as of October 2020, there were only 20 providers of this service. Eleven of the twenty service areas had no providers. Providers report that the rate model for this service does not cover their costs to provide Supported Living services. There remains general confusion among Medicaid enrollees, Support Coordinators, and

potential service providers about Supported Living, including questions as to how it operates, who can be supported using this service, and licensing requirements.

Independent Living Supports is the only service available in the Building Independence (BI) waiver that is not available in other waivers. In essence, this means that the state is administering and operating an entire 1915(c) waiver for one service. The level of effort and resources required to operate a waiver are significant. Operating an entire 1915(c) waiver for one service is not a prudent use of valuable resources. In addition, because personal assistance was not included as a BI waiver service, the BI waiver meets the needs of very few individuals on the Priority One waitlist. Many people on the Priority One waitlist who are offered a BI waiver slot turn it down and continue to wait for a Community Living (CL) or Family and Individual Supports (FIS) waiver slot. If there are no individuals on the Priority One waitlist willing to accept a BI waiver slot, a regional Waiver Slot Assignment Committee session is held to assign the BI waiver slot(s) to individuals meeting criteria from Priority Two and then Priority Three waitlists. This practice is not consistent with assigning waiver slots based on priority of need.

Shared Living has been an available service in all three DD waivers since 2016. Yet, as of April 2020, there was one provider enrolled to be the administrative provider of shared living services. Providers report that the requirements and expectations of the administrative provider generate risk and liability concerns. In addition, providers report a lack of service structure that facilitates and supports an individual to successfully transition in a person-centered and individualized manner to their own home or apartment. These concerns, coupled with an inadequate rate to cover the administrative provider costs to provide this service, create a disincentive for providers to enroll as an administrative provider of Shared Living. Additionally, there is confusion among individuals and families, Support Coordinators, and potential service providers about many aspects of the Shared Living service, including allowable roommates and the availability of additional services and supports to meet an individual's needs.

Assistive Technology, Environmental Modifications and Electronic Home-Based Supports are services that provide individuals with greater autonomy and independence. In peer-to-peer interviews, self-advocates shared information about innovative uses of technologies and supports that add to their independence, sense of security, and overall well-being. However, these services are often not used to their maximum benefit due to the complexities of service authorization and access, lack of provider capacity, and in some cases, service funding caps that do not cover the cost of a specific technology or home modification. These services are sometimes provided by a private provider that can reduce the actual benefit to the individual through provider fees. As individuals and their families know what items will best meet their needs, allowing a fee-charging "broker" reduces the individual's ability to obtain needed Assistive Technology, Environmental Modifications and Electronic Home-Based Supports.

Assessed Employment and Day Services

Supported Employment services in Virginia need innovation and transformation to modernize the culture and expectations of employment for individuals on the DD waivers. Interviewed individuals reported that the success of their employment depended greatly on the creativity of their job coaches. Others reported that they were essentially turned away from employment services because of their needs for support in the workplace. Many support coordinators, families, and others within the system assume that employment is not a viable choice for individuals who need a higher level of support in finding and maintaining employment. This assumption is also evident in the lack of creativity in helping individuals customize a job that benefits both the employee and employer. Change must address the root causes of inconsistency in the experience of individuals and families as well as the practices that create inconsistent results.

System-wide factors contribute the inconsistency in quality of service. First, the current employment service model is based on an hourly rate model that does not incentivize job placement and retention. Additionally, Department of Behavioral Health and Developmental Services data and reports of the Independent Reviewer show that barriers to employment are often not meaningfully addressed. Further, little effort is made to educate individuals about employment after they indicate they are not interested in working during ISP meetings.

There is limited understanding of supported employment policy, practice, and expectations across the DD waiver services system and among critical partners. This knowledge gap has a negative impact on people with disabilities who are interested in employment. There is also a knowledge gap on the impact of paid employment on a person's Medicaid and Social Security benefits. This lack of understanding is sometimes fueled by misinformation about options regarding working, how to begin employment, and the impact employment on an individual's state and federal benefits.

Waiver funds cannot be used to support sheltered workshops in Virginia. Yet, DBHDS has reported that some individuals participated in sheltered workshops using DD waiver funding. DBHDS attributes this count to individuals attending a waiver-funded day program that also offers sheltered workshop activities. Even when waiver funds do not directly support sheltered workshops, it raises the question of whether waiver-funded day programs financially benefit sheltered workshops.

Community Engagement, Community Guide, Community Coaching and Workplace Assistance. While Community Engagement waiver services authorizations have increased 38 percent since 2017, growth has remained relatively level since 2018. Individuals on all three waivers are eligible both for Group Day and Community Engagement, yet Community Engagement continues to lag far behind Group Day in terms of the percentage of people on the waivers using that service in all regions. Providers indicate interest in Community Engagement but find

V

the rates are insufficient for the service. For safety and best practice, many providers require at least two staff members to accompany individuals in the community. Providers report the rate does not support a 2:3 staffing ratio, and thus providers do not feel they can offer the service safely or to individuals who may need 1:1 support for community activities.

Overall service authorizations for the integrated day services increased 1.4 percent from June 2019 to June 2020. The number of providers for Workplace Assistance, Community Guide and Community Coaching remains small and unevenly distributed across the state. For individuals to benefit from these services, there must be providers with the capacity to serve them. Many individuals would qualify for a mix of Community Engagement, Group Day and Community Coaching services, yet providers report that the paperwork required for each service discourages them from providing a mix of services to the individual.

Individual Empowerment in the DD Services System

Individual Empowerment is an essential element for a person-centered system of services and support. In peer-to-peer interviews, individuals with disabilities expressed the importance of not only being listened to, but being heard. The system of services and supports they rely on does not often embrace the voices and choices of self-advocates. Individuals and families experience service planning discussions that lack depth and a sincere interest in supporting individual choice. Some individuals and families express a high regard for their support coordinators who are always available to answer questions and open to out of the box thinking and service options. Others report a different experience including unreturned phone calls, preconceived notions about competence and abilities, and more concern over paperwork and process than for what is important to the individual.

There is a lack of creativity and flexibility in developing support plans that reflect the array of service options designed to better support meaningful inclusion in all aspects of community life. The experience and expertise of self-advocates, who have the greatest investment in the system of services and supports on which they depend, are often missing from critical decision-making and opportunities to educate those charged with authorizing, monitoring, and implementing services.

Individuals who currently live independently or are interested in more independent options indicated that budgeting was one of the most important skills they needed to learn to successfully live on their own.

Currently, peer mentors are limited to individuals who currently or previously used waiver services and have lived independently for at least 12 months. Requiring a peer mentor to have "lived independently in the community for one year" overly limits the potential pool of knowledgeable and supportive mentors.

The Commonwealth Focuses on Efforts to Improve Service Availability and Utilization

As part of waiver redesign and compliance with the Settlement Agreement, the Commonwealth has taken positive steps to improve the availability and utilization of integrated residential, day, and employment services. The Department of Behavioral Health and Developmental Services has partnered with state housing agencies to offer more financial supports for independent living. New training was developed for support coordinators in 2020, and provider development and outreach is ongoing.

Additionally, formal state efforts are underway to address two important factors influencing slow progress with many of the new services over the past five years: 1) insufficient provider rates, especially with new services that many providers contend lacked fully realized costs when the rate assumptions were developed; and 2) the lack of regulations and a provider manual for the DD waivers.

While these assessments identify barriers to the growth of integrated residential, day and employment services, the Virginia Board for People with Disabilities recognizes the concerted and ongoing efforts of the Commonwealth to address service challenges. The Board offers 23 recommendations, grouped by three topic areas, to strengthen and support these efforts.

Recommendations to Increased Access to Independent Living

Supported Living

Recommendation 1: The General Assembly should support the goals of the Settlement Agreement and waiver redesign to incentivize integrated and independent living options by establishing rates for the provision of supported living services that are comparable to the rates for the provision of group home residential services.

Recommendation 2: The Department of Behavioral Health and Developmental Services (DBHDS) should resolve inconsistent practices among licensing specialists when licensing Supported Living to ensure it is the provider that requires licensure, rather than the apartment/home being a DBHDS licensed setting.

Recommendation 3: The Department of Medical Assistance Services (DMAS) should clarify and resolve conflicting information in the waiver regulations located at 12VAC30-122-540, which states that the supported living “provider shall be licensed” but also describes supported living services being provided in a “DBHDS licensed settings.”

Recommendation 4: DBHDS and Community Services Boards should ensure that support coordinators have a comprehensive understanding of supported living services, including the differences between supported living and in-home supports. Support coordinators must be

knowledgeable and accurate when explaining to individuals and families the various service options and opportunities available in the DD waivers, including supported living services.

Independent Living Supports

Recommendation 5: DMAS should add the Independent Living Supports service to the Family and Individual Supports (FIS) waiver. All individuals on the Building Independence (BI) waiver should seamlessly transition to the FIS waiver, and the BI waiver should be eliminated.

Shared Living

Recommendation 6: DBHDS should develop engaging vignettes of individuals with disabilities participating in shared living. Vignettes should represent different shared living situations and the additional services and supports an individual receives. Vignettes can depict different roommate situations (e.g., sibling, friend, matched roommate), differences in how people spend their days and evenings, and the use of assistive technology and electronic home-based supports to facilitate greater independence. The vignettes should be added to the Shared Living Toolkit and shared broadly with support coordinators, providers, individuals and families.

Recommendation 7: DMAS and DBHDS should include the monthly reimbursement rate for the administrative provider of shared living services in the review of payment rates for services provided in the DD waivers currently required to be submitted to the General Assembly by November 1, 2021 (HB 1800, Item 320 #9C) and ensure that the rate assumptions accurately reflect service delivery design and cost.

Recommendation 8: DBHDS should implement a pilot project with providers interested in becoming an administrative provider of shared living services. These providers should receive training and technical assistance as they move through the process of supporting individuals to transition to shared living and providing the administrative services. There should be a strong research and evaluation component to the pilot project to: 1) identify and address barriers and 2) identify needed modifications and innovations to policy and practice to ultimately increase provider capacity and service utilization. DMAS and DBHDS should directly address provider concerns about their exposure to risk and liability based on the responsibilities and expectations of the administrative Shared Living provider outlined in regulations. Incentives should be provided to participating providers to reimburse them for their time and expertise.

Assistive Technology, Environmental Modifications, Electronic Home-Based Supports, and Other Services

Recommendation 9: DMAS should explore options to provide Assistive Technology, Environmental Modifications and Electronic Home-Based Supports as a Consumer Directed Service.

Recommendation 10: DMAS should allow the \$5,000 cap on Assistive Technology, the \$5,000 cap on Environmental Modifications, and the \$5,000 cap on Electronic Home-Based Supports to be a combined \$15,000 cap across all of these services. DMAS should seek the approval of the

General Assembly if needed. This will increase an individual's ability to purchase necessary but expensive services, without increasing the total cost allocation for services.

Recommendation 11: DMAS should make financial literacy training an allowable activity for transition planning services or as part of the benefits planning service.

Recommendations to Increase Access to Employment and Integrated Day Services

Competitive Integrated Employment

Recommendation 1: The General Assembly should direct the Department of Aging and Rehabilitative Services (DARS), DMAS, and DBHDS to study options for designing and implementing a value-based purchasing model for supported employment services in Virginia. The study should include an assessment of other states like Wisconsin that use a value-based purchasing model to reward providers for supporting individuals with a spectrum of support needs in sustained job placements.

Recommendation 2: DBHDS should invest in training and resource development to cultivate a pool of supported employment subject matter experts who can provide technical assistance to support coordinators and others navigating the complex processes for accessing supported employment services.

Recommendation 3: DBHDS should require support coordinators to educate individuals with disabilities and their families about the basic impact of employment on benefits and the Benefits Planning service prior to the official Individual Support Plan meeting, consistent with the DOJ Settlement Agreement Compliance Indicator #14.

Recommendation 4: The Commonwealth of Virginia should develop and implement a plan to phase out sheltered employment settings and the use of Section 14(c) certificates of the Fair Labor Standards Act (FLSA). Resources should be shifted to support competitive integrated employment and individuals currently served in sheltered employment settings should be transitioned into competitive integrated employment. This is similar to a recommendation in the VBPD's 2017 Employment Assessment.

Recommendation 5: In the next Semiannual Report on Employment Services, the DBHDS should clarify the use of Medicaid HCBS funding to fund services in sheltered workshops.

Recommendation 6: The Commonwealth must ensure employment is accessible to all people on the DD waivers, including those with higher support needs. DARS and DBHDS should explore ways to invigorate customized employment in Virginia, including adding customized employment as a unique and unduplicated service in the DD waivers that would provide more hours for job exploration, job tailoring, coaching, and extended assistance to employers.

Recommendation 7: DBHDS should add to their data tracking the number of individuals in waiver employment by SIS level to support the development of employment strategies for all. DBHDS should provide a summary of this data in their Semi-Annual Report on Employment Services.

Integrated Day Services

Recommendation 8: DBHDS and DMAS should develop provider capacity benchmark goals based on service need estimates regionally for Workplace Assistance, Community Guide and Community Coaching and develop incentive options and other strategies to increase provider capacity to meet the benchmark goals.

Recommendation 9: DMAS and DBHDS should explore options to streamline and eliminate redundancy in the Plan for Supports across day services when one provider is providing multiple services including Community Engagement, Group Day, and Community Coaching services.

Recommendation 10: DMAS and DBHDS should ensure the reimbursement rate for the provision of Community Engagement accurately reflects service delivery design and cost including a service delivery model of two staff and three individuals in the community.

Recommendations to Further Individual Empowerment in the DD Services System

Recommendation A: DBHDS should incentivize Community Service Boards, possibly through a pilot project, to incorporate self-advocates in paid positions to bring perspective and experience to the training of support coordinators, including adding a self-advocate-led module in the required support coordinator training modules. The self-advocates can provide guidance through lived experience on the education of individuals and families about services and supports and advise on the principles of person-centered planning and individualized supports.

Recommendation B: DMAS should consider establishing and seeking General Assembly approval of person-centered facilitation as a distinct, non-duplicative waiver service that would provide more support and expertise to tailor service options to an individual's needs and goals like in Kentucky, where "person-centered coaching" services provide "for modeling, monitoring, assessing and implementing the person-centered plan.

Recommendation C: DMAS and DBHDS should broaden the qualification requirements for Peer Mentors to include competitive integrated employment and/or demonstrated leadership abilities and leadership roles in organizations and in their communities. A peer mentor could be a person who chooses to live with their family, is competitively employed and actively involved in the community with a robust social life.

Purpose

This report includes two targeted assessments of relatively new services in the Developmental Disability waivers. First, the Board offers an assessment of new services available in the DD waivers intended to provide options and opportunities for living in the most integrated community settings. Second, the Board presents an assessment of supported employment and new services available in the DD waivers intended to provide options and opportunities for integrated, non-center based day services. These services were added when the waivers were redesigned in 2016. The goals of the waiver redesign included the following:

- *Better support individuals with intellectual and/or other developmental disabilities to **live integrated and engaged lives in their community**,*
- *Offer services that **promote community integration and engagement**,*
- *Improve the capacity and quality of providers by increasing their compensation as they increase their expertise,*
- *Align with current research to **achieve better outcomes for individuals supported in smaller community settings**, and*
- ***Meet the Commonwealth's obligations under the community integration mandate of the ADA, the Supreme Court's Olmstead Decision, and the 2012 DOJ Settlement Agreement** requirements to create a community system of care.*

(The Department of Medical Assistance Services and the Department of Behavioral Health and Developmental Services, 2015. Emphasis added.)

The purpose of both assessments is to determine the extent to which the new services have furthered the goals of Virginia's redesign of the 1915(c) HCBS waivers, referred to as the DD waivers, and to provide recommendations to further advance these goals. Virginia is now five years post redesign of the DD waivers, and many goals have yet to be fully realized. As detailed in these assessments, the new waiver services reviewed have had relatively slow or static rates of growth.¹

Methodology

To assess residential, new day, and employment services in the DD waiver, the Board analyzed Virginia-specific data, conducted interviews and surveys about individual, family and stakeholder experience with the DD waiver system, and reviewed national research on trends and best practices in HCBS waiver services.

¹ Two important factors influencing slow progress with many of the new services over the past five years are 1) insufficient provider rates, especially with new services that many providers contend lacked fully realized costs when the rate assumptions were developed; and 2) the lack of regulations and a provider manual for the DD waivers. These two factors are critically important for systemic change of the disability service system to be meaningfully achieved. Formal state efforts are underway to address these challenges so these assessments do not address them in depth.

Data and Published Research

The Board reviewed waiver service data provided by DBHDS and DMAS. The Board requested tailored data sets as well as reviewed previously published reports by the state agencies, national data and reports, reports of the Independent Reviewer and reports from the National Core Indicator project led in Virginia by the Virginia Commonwealth University Partnership for People with Disabilities. For a full list of the resources consulted in the report, see Works Cited.

Interviews and Surveys

To better understand the experience of individuals using services available in the DD waivers, the Board worked in collaboration with the Arc of Virginia to organize and conduct seven peer-led focus group discussions. A total of 34 individuals who use waiver services participated in the focus groups.

To better understand the perspective and experience of family members and guardians of individuals who use waiver services, the Board conducted an online family member survey. A total of 49 eligible family members/guardians completed the online survey.

In addition, the Board conducted group and individual interviews with stakeholders, representing advocacy organizations and service providers conducted in March and April 2021. For more information about the focus group discussions, family member survey, and advocate and provider interviews, see the appendices.²

Background: Transforming Services to Promote Inclusion and Integration

The Americans with Disabilities Act (ADA,) and the *Olmstead* decision set clear expectations that states will deliver services and supports in integrated, community-based settings. Today, Virginia provides a wide range of services including residential, day and employment long-term services and supports to individuals with developmental disabilities (DD) through Medicaid waivers authorized by Section 1915(c) of Title XIX of the Social Security Act. These 1915(c) waivers allow states to waive provisions of the Medicaid statute to provide Medicaid Home- and Community-Based Services (HCBS) to eligible individuals who would otherwise receive institutional care. These services are funded in part by the federal government and in part by the state.

This section provides a brief background on the federal and state laws and policies that have reshaped Virginia's Medicaid waiver services for people with developmental disabilities (DD) to promote community integration. Understanding the goals of laws and policies gives a clear framework for assessing the progress of the DD waiver systems and the barriers that remain in achieving these important goals.

² This report does not reflect the significant impact of the COVID-19 pandemic. Participants in focus group discussions, interviews, and the family member survey were asked to provide feedback based on their pre-COVID-19 experience.

The Integration Mandate of the ADA

The ADA requires that the Commonwealth serve individuals with disabilities receiving Medicaid-funded services in the most integrated settings possible, consistent with the individual's informed choice. While support for community services grew in the last decades of the twentieth century, many individuals with DD were still served in large, congregate care settings, such as training centers. These large residential settings were known as "institutions" and provided residents limited opportunity to engage with the broader community.

In the landmark 1999 case, *Olmstead v. L.C.*, the United States Supreme Court found that "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable of or unworthy of participating in community life" and that "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."

The Court held that Section II of the ADA requires states to provide community-based services when "the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities." The Court's holding in *Olmstead* is known as the ADA's "integration mandate."

The next year, Congress would echo the integration mandate in the *Developmental Disabilities Assistance and Bill of Rights Act of 2000*, (P.L. 106-402) (DD Act) stating 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."

Complying with *Olmstead*: DOJ Settlement Agreement

As federal law established the right to community-based services, the United States began enforcing the integration mandate through investigations into many states' institutional care systems. In 2008, the Department of Justice (DOJ) began an investigation into the Central Virginia Training Center (CVTC) to determine compliance with *Olmstead* and the ADA. CVTC, like the state's other training centers, is a large hospital-like facility that provided services to 357 residents with developmental disabilities in 2012. Finding that the availability of community-based services for CVTC residents was affected by Virginia's statewide approach to disability services, DOJ widened its investigation to include the Commonwealth's approach to service delivery for all individuals receiving or eligible to receive services in an institutional setting.

In 2012, the Commonwealth entered a settlement agreement with DOJ to expand the provision of home- and community-based services for the "Settlement Class," which included current

Training Center residents, people with disabilities in other segregated settings, and people on the waiting list for services. The agreement sets out to achieve the goals of community integration, self-determination and quality services in the provision of Virginia's Medicaid Home and Community-Based Services. While the agreement was consistent with Virginia's ongoing effort to transition from an institutional model of care to a community-based system, the presiding judge noted that the agreement "dramatically changes the way Virginia provides services to its intellectually and developmentally disabled population." The Commonwealth made specific commitments related to Community Living, Employment, and Day Services to help individuals participate more fully in their communities. Through residential and employment service innovations, Virginia would develop a system of services and supports that enable individuals using waiver services to live and work in the community based on their interests and lifestyle choices.

Evolving Federal Framework: Virginia's HCBS Transition Plan

While Virginia began implementing its *Olmstead* initiative at the state level, the Centers for Medicare & Medicaid Services (CMS) changed Medicaid HCBS funding requirements to better align with the expectations of the ADA and *Olmstead*. CMS introduced new regulations in 2014 to promote waiver services that foster individual autonomy and community participation. Referred to as the "HCBS Settings Rule," (42 CFR Parts 430, 431, et. al.), the regulations require states to develop Statewide Transition Plans (STP) to ensure that recipients of Medicaid waivers receive services in settings that facilitate community engagement and self-determination. Each service setting must optimize independence in making life choices, ensure the individual's rights of privacy, dignity and respect, and be integrated with the greater community to receive Medicaid HCBS waiver funding.

Transforming Services

The Commonwealth's combined obligations under the ADA, the DOJ Settlement Agreement, and the new HCBS settings rule created a need to re-envision disability services in Virginia. In 2016, Virginia overhauled its Intellectual Disability, Developmental Disability, and Day Support Waivers and waiver services. The Department of Medical Assistance Services (DMAS) and Department of Behavioral Health Developmental Services (DBHDS) redesigned these waivers to comply with Settlement Agreement, expand opportunities for HCBS in smaller, more integrated settings and to incentivize providers to adapt their services to support community integration (DMAS and DBHDS, 2015).

The redesigned waivers, collectively referred to as the DD waivers, are the Community Living (CL), Family and Individual Supports (FIS), and Building Independence (BI) waivers. Prior to the 2016 waiver redesign, the Commonwealth offered different waivers for individuals with Intellectual Disabilities and individuals with Developmental Disabilities. With the new redesigned waivers, both populations may be eligible for all three waivers. When waiver redesign occurred, people receiving services in the pre-redesign waivers seamlessly transitioned to the new comparable waiver. The chart below shows the waivers available pre-

and post-redesign (Figure 1).

FORMER WAIVER	NEW WAIVER	PURPOSE
Intellectual Disabilities	Community Living	This waiver is available to both children and adults. People with this waiver may require supports in their homes all the time. Some people may live in these group homes with staff and may need supports with complex medical and/or behavioral needs.
Developmental Disabilities	Family and Individual Supports	This waiver is available to both children and adults. People with this waiver may live with their family, friends, or in their own homes. Some people may need supports with some medical and/or behavioral needs.
Disability Services	Building Independence	This waiver is for adults 18 years and older who are able to live independently. People with this waiver usually own, lease, or control their own living arrangements and supports are complemented by non-waiver-funded rent subsidies.

Figure 1: Descriptions from Virginia DBHDS Guide, “Navigating the Developmental Disability Waivers: A Guide for Individuals, Families, and Support Partners,” (June 2019).

Enrollment by Waiver Type

In September 2020, 14,952 children and adults were enrolled for services available in the DD waivers. Currently, the most highly utilized waiver is Community Living (see Figure 2). This is primarily due to the higher utilization of the Intellectual Disability waiver pre-redesign, and the transition of those individuals to the CL waiver. 77.5 percent of individuals are on the CL waiver, 20.2 percent on FIS and only 2.3 percent on the BI waiver (Figure 2).

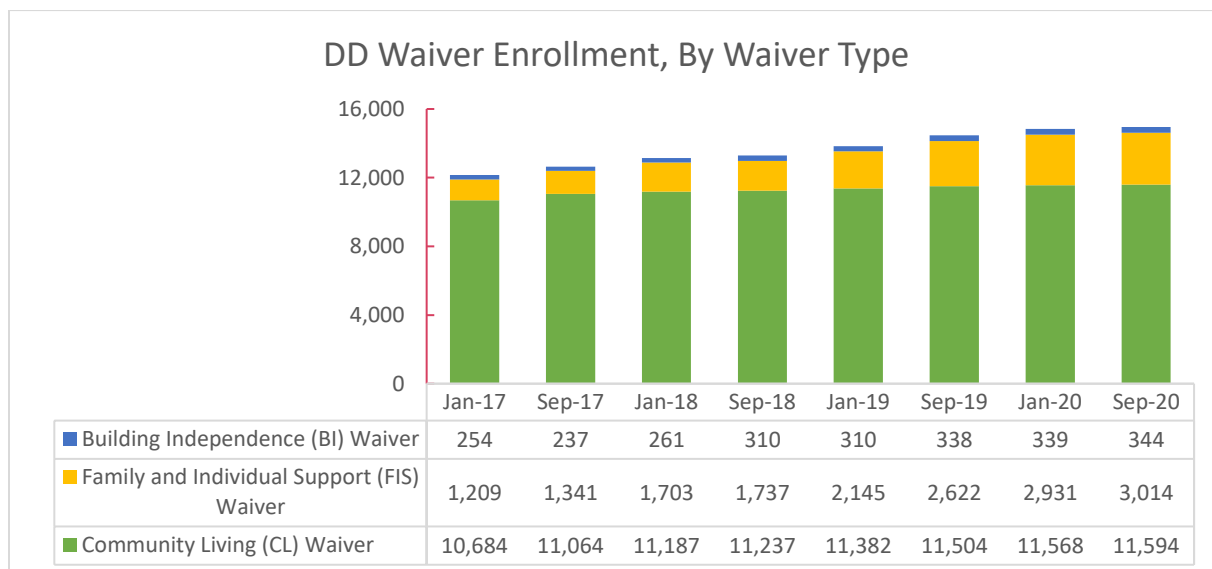


Figure 2: DBHDS Waiver Enrollment over time.

Assessment of New Residential Services Available in the DD Waivers

Landscape: Options and Trends in Services

This assessment addresses the new residential services and supports that were added to Virginia's Developmental Disability waivers with the aim of providing more independent living options. Virginia considers living options to be independent if they have the following characteristics (Virginia DBHDS, 2021):

- The individual does not reside with a parent, grandparent, or legal guardian;
- The individual lives in housing types that anyone without a disability can live in, based on income;
- The individual has social, religious, educational and personal opportunities to fully participate in community life;
- Housing is affordable (i.e., the individual pays no more than 30-40 percent of his/her adjusted gross income);
- Housing is accessible (barrier free);
- Housing is leased/owned by the individual; and
- Housing is not contingent upon participation in services (and vice versa).

The assessment will first discuss independent living overall, including its importance and prevalence, and then evaluate the extent to which the three new residential services have furthered independent living in Virginia.

The Value of Meaningful Choice: A National Trend toward Integrated, Independent Living Options

Integrated, Independent Living Options are Essential for the Autonomy of People with Disabilities

There is substantial research showing physical and psychological benefits for people with DD who live in more integrated settings. National research studies have consistently shown that individuals with DD have greater satisfaction, self-determination and privacy when they reside in smaller settings (Houseworth, 2018). The National Council on Disabilities reviewed 45 peer reviewed research studies, meta-analyses, policy reports, and other documents and found that:

“People with IDD who lived in a home of their own, with their families, in Shared Living situations, or in provider supported alternatives with one or two roommates consistently scored higher in terms of individual outcome achievement than did people living in moderate (four to six individuals) and large (15 or more residents) residential programs and facilities” (National Council on Disabilities, 2015).

Individual outcomes assessed included autonomy, ability to make choices, and satisfaction with life and living situation. There is also state research that demonstrates the benefits of living in more integrated settings. In Virginia, individuals who live independently report high levels of satisfaction. Eighty-seven percent of individuals living in their own home or apartment liked their home (National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute, 2020).

Self-Advocates' Perspectives on Independent Living

In peer-led focus groups of adults using waiver services, participants living in their homes echoed research that independent living encourages autonomy and satisfaction with life.³ All 23 participants who lived in their own home or Supported Living apartment expressed satisfaction with their living arrangements. With the help of family, friends, support providers and assistive technology, these participants enjoyed living on their own, having more privacy and learning independent living skills like cooking, cleaning, and budgeting. Many of the participants were also competitively employed in the community and/or active volunteers in civic organizations. Several of the participants expressed satisfaction that they lived on their own just like their adult siblings.

Despite high satisfaction with their living arrangements, many participants said the process to find their own home required support and strong self-advocacy. Several of the participants who had previously lived in group homes or with their family spoke with their family and support coordinators about their desire to live more independently. Seventeen participants said that the support of family was key in helping them find a home and organizing the supports to live independently. Individuals who had no family support said that they navigated the system on their own and with the help of support coordinators.⁴

Participants who lived with their families or in group homes also expressed interest in living more independently but were concerned about receiving adequate supports, such as 24 hour/seven day a week support in their own homes. In some cases, family members or support coordinators had told them that living in their own home was not feasible, even when the individual wanted to live more independently.

Yet, individuals with higher support needs can and do live on their own. One participant with significant medical supports described satisfaction in living in his own apartment with 24/7 support, as well as the significant self-advocacy it took to make living independently possible:

"Of course my Caseworker did the paperwork part, the bureaucratic part, but I really did most of the legwork of doing the research to find what was the best place for me. They gave me a lot of bad options, either like

³ See Appendix A for a description of focus group participants.

⁴ For consistency, this assessment uses the term "support coordinator" when referring to individuals also known as "case managers."

living in a nursing home or alone in my apartment and not getting enough hours for me to feel safe about it.”

His experience underscores the advice of other focus group participants, who emphasized the importance of speaking up about what they want and where they want to live.

Independent Living Options are Rarely Utilized Nationwide and in Virginia

Despite the benefits of integration, the system of services and supports in Virginia and nationwide has historically focused on larger congregate living settings, smaller group home models, and the family home as place of residence. The old adage among many disability rights advocates is that “people choose what they know.” If people with disabilities or family members do not know of other options, have not had the opportunity to see and experience other options, or do not trust in system to effectively support individuals interested in greater independence, real choice is not available.

A small, albeit growing, number of Virginians with disabilities live independently. As of September 2020, 4.5 percent (670) of adults on the three DD waivers lived independently in their own home (Virginia DBHDS, 2020). While a small overall percentage, it reflects a 213 percent growth rate in total number of adults living independently since 2016 (Figure 3).

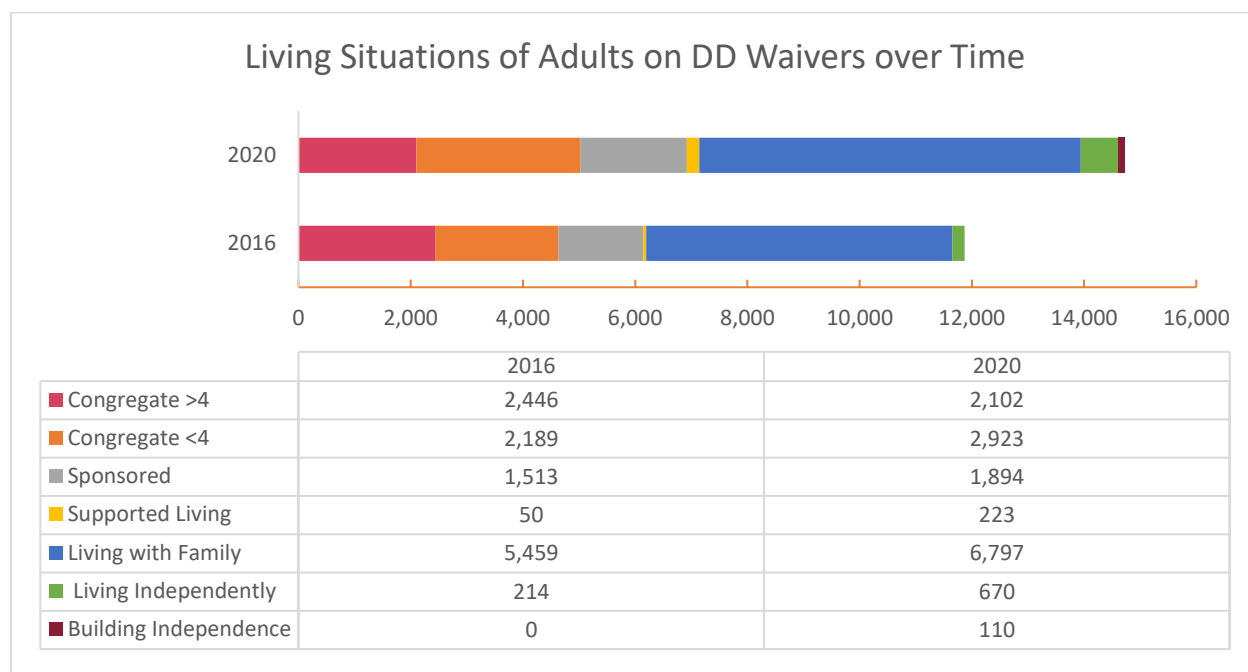


Figure 3: Virginia Department of Behavioral Health & Developmental Services (2020). Residential Settings Trend Report FY 2021, Quarter 1

Most other states serve a greater proportion of people with disabilities in independent living settings than Virginia. In 2017, Virginia ranked 38th out of 44 states surveyed in the percent of

LTSS recipients with DD who lived in their own homes. Nationwide, approximately 14 percent of individuals with DD who received Medicaid Waiver services lived in their homes in 2017 (Larson, et al, 2020).

There may be untapped demand for independent living services nationwide and in Virginia. Many individuals nationwide currently live at home with family. While this arrangement works well for many people, others desire more independence. A National Core Indicators study found that nationally, of young adults aged 18-25, 66 percent lived in the family home as of 2016. 29 percent reported that they would like to live somewhere else (Giodorno & Bradley, 2018). In a VBPD survey of family members of people with developmental disabilities, 15 of 37 (41 percent) respondents said their family member was *“interested in living in a more independent living situation (e.g., their own home/apartment with or without a roommate) with the supports they need.”*

Additionally, demand for independent living options is likely to grow in the future. Many family caretakers of individuals with DD are aging. Of more than 143,000 family caretakers in Virginia in 2017, 17.2 percent were older than 60 years (Tanis et al, 2020). As family members age, individuals with DD will need additional supports to remain in community-based settings of their choice.

Virginia Has Made Several Efforts to Reduce Barriers to Independent Living, but Additional Work Is Needed

Three types of barriers have likely contributed to the underutilization of independent living options in Virginia. These barriers include financial barriers, educational barriers, and service barriers. The Commonwealth has undertaken several efforts to address these barriers, since entering the Settlement Agreement all of which are commendable. However, the utilization data presented in the last section demonstrates that additional actions are needed to ensure that real choice and options are available.

Virginia has made strides in increasing different forms of financial support for individuals with DD who wish to live independently. In a VBPD survey of family members of people with developmental disabilities, six out of 12 (50 percent) respondents said that difficulty finding affordable housing “moderately” or “significantly” contributed to their lack of access to independent living options. Housing vouchers play a key role in allowing people with disabilities who have a low income to maintain their own home. As of September 2020, the Commonwealth had made 993 rental assistance resources available to the Settlement Agreement population, which includes people receiving and waiting for the DD waivers.

The Commonwealth has also developed a number of other resources designed to support and educate people with disabilities to move into their own homes and maintain tenancy. People often do not know what resources are available, or have concerns that need to be addressed first regarding, for example, health and safety or assistance with system navigation. DBHDS has five Regional Housing Coordinators to develop local, regional and statewide relationships. The

coordinators identify resources necessary to increase the availability of and access to affordable and accessible housing for individuals with a developmental disability housing vouchers. In addition, DBHDS has developed multiple instruments and tools to guide and support access to independent housing such as a Creative Housing Approaches Guide, My Own Home Guidebook, FAQs, and Independent Housing webinars.

New Options for Independent Living: Supported Living, Independent Living Supports and Shared Living Services

The Commonwealth added three new waiver services to help people obtain the services and supports they need to live more independently in smaller community-based settings that allow for personal autonomy. These services, which are the focus of the rest of this assessment, include Supported Living, Independent Living Supports, and Shared Living. Figure 4 provides a description of each service and the waiver in which the service is available.

Residential Service	BI	FI	CL	Description
Supported Living		✓	✓	This service provides residential support to individuals living in an apartment or home operated by a licensed provider. The service supports skill-building, routine supports, general supports, and safety supports that enable the individual to acquire, retain, or improve self-help, socialization, and adaptive skills necessary to live a self-directed life in home and community settings. This service requires around-the-clock availability of paid provider staff who have the ability to respond in a timely manner (12VAC30-122-540).
Independent Living Supports	✓			This service provides skill-building and supports necessary to promote the individual's stability in his or her own home and community, increase socialization, maintain health and fitness, promote decision-making and self-determination, improve skills with activities of daily living (ADLs), and support transportation to and from community locations and resources. Individuals who are in support needs levels one or two may typically receive 14 or 21 hours, respectively, of independent living supports per week. Independent Living Supports do not include Personal Assistance services (12VAC30-122-420)
Shared Living	✓	✓	✓	Shared living aims to foster natural supports by reimbursing a portion of the room and board for another adult who lives with the individual with a disability and provides non-paid support. The support person is a roommate who is not a parent, guardian or spouse to the person with a disability. Together, they live in a home or apartment owned or leased by the person with a disability. The type of supports provided are based on a written agreement between the individual and the roommate. Supports can include fellowship, limited help with ADLs, meal preparation, light housework and medication reminders. The person with a disability living in a Shared Living arrangement is able to access other waiver services including in-home supports, personal assistance, and, if on the BI waiver, independent living supports (12VAC30-122-510).

Figure 4: Definition of Residential Waiver Services

Utilization and Provider Trends for the New Residential Services

While utilization of Virginia's new residential services has grown over time, their use remains limited. Two of the new waiver services, Independent Living and Supported Living, have been increasingly utilized each year since 2017. Yet, both services have seen the rate of growth decline each year after 2018. Shared living, the third new residential service, has only served two individuals since 2017 (Figure 5). According to the DBHDS Provider Summary Report, service authorizations for all three new residential services only accounted for about three percent of total residential service authorizations under the waivers (Virginia DBHDS, November 2020).

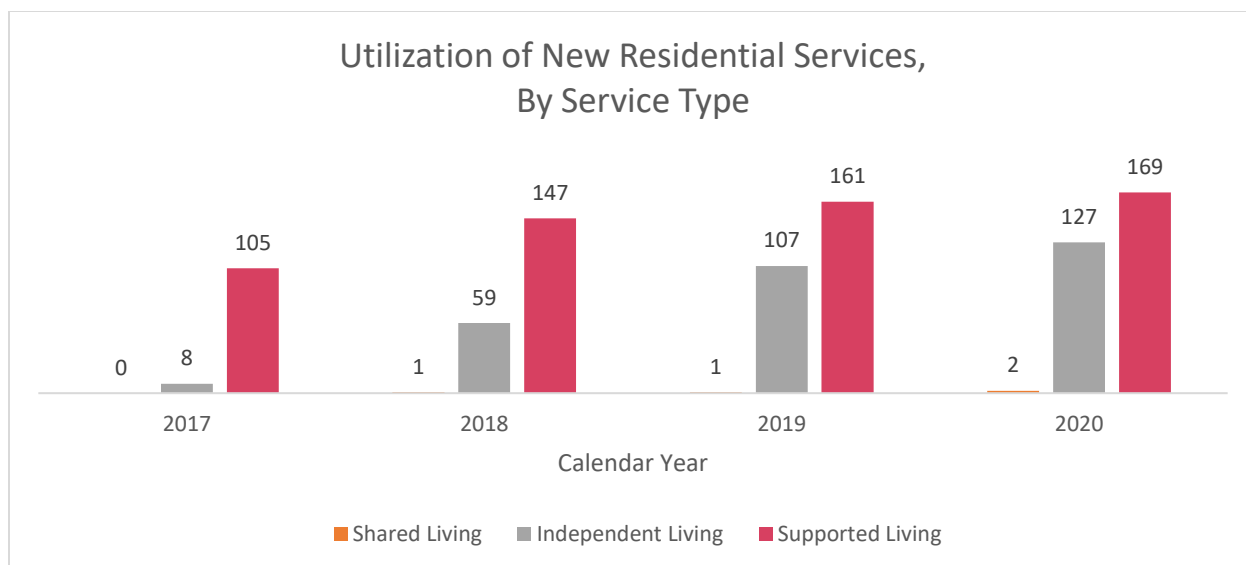


Figure 5: Unduplicated service utilization member count based on claims data by calendar year (Department of Medical Assistance Services)

Far fewer people have utilized the services than are eligible. Supported Living services are currently used by only 0.8 percent of individuals on either the FIS or CL waivers in 2017. By 2020, that number had increased to only 1.2 percent. Independent Living Supports (ILS) were used by an estimated 39 percent of people on the BI waiver in 2020, the only waiver in which ILS is an available service. One possible reason for the low utilization of ILS is that the people who transitioned to the BI waiver, when it was first created, were not required to live independently, like new BI waiver enrollees are required to do.

Development of Provider Network for New Residential Services Has Been Limited

One of the reasons for the low service utilization may be a limited provider network. One of the key aims of waiver redesign was to “... [i]mprove the capacity and quality of providers...” to offer more integrated services “...by increasing their compensation as they increase their expertise” (DMAS and DBHDS, 2015). Available data on provider networks indicate that the Commonwealth is not on track to achieve this goal.

Providers have been slow to offer Supported Living, Independent Living, and Shared Living services. The chart below shows that fewer providers offer these new waiver services compared to the ongoing waiver services of Sponsored Residential and In-home supports (Figure 6). The number of providers of new residential waiver services in 2020 ranged from just two providers of Shared Living to 23 providers of Independent Living Supports. Meanwhile, the number of providers of ongoing residential waiver services ranged from 74 providers of Sponsored Residential services to 117 providers of In-Home Supports.

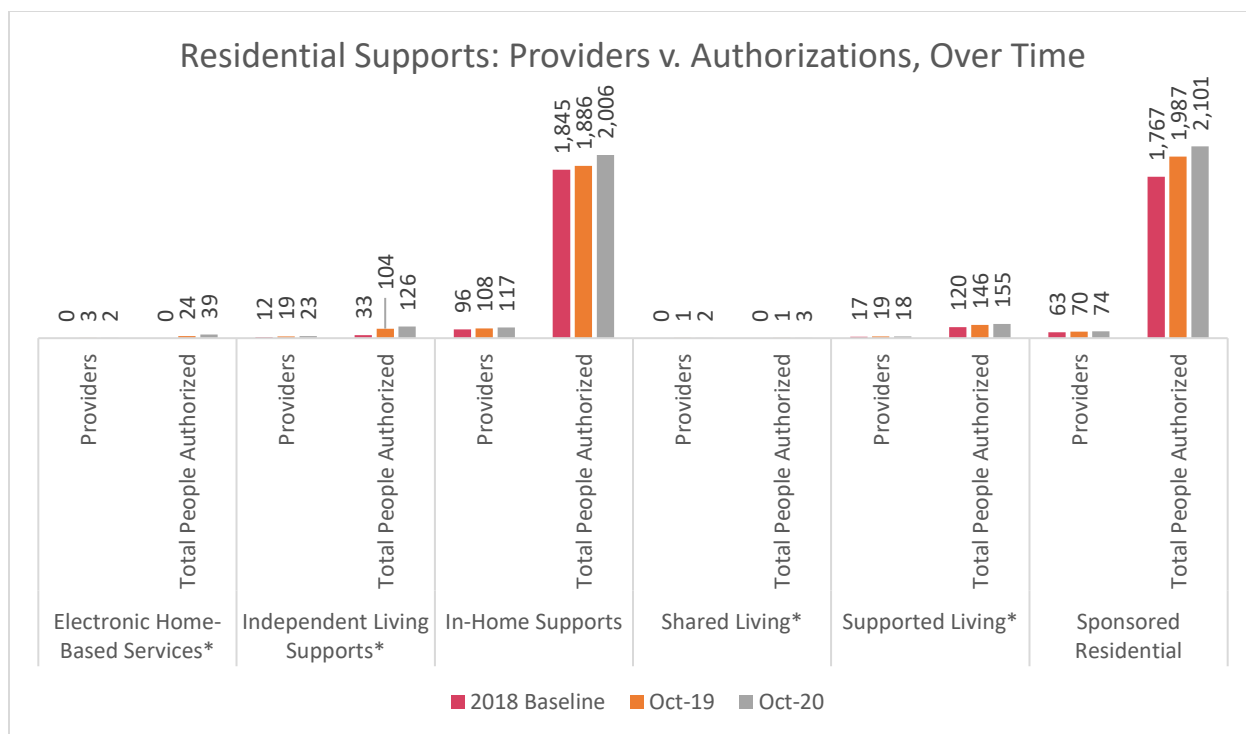


Figure 6: DBHDS Provider Data Summary, November 2020

Depending on where an individual resides in Virginia, they may have even less access, or no access, to the new residential waiver services. Only two of Virginia's five regions had Shared Living providers in October 2020, and there was only one provider in each of these two regions. Northern Virginia only had one provider that offered Independent Living Supports, and a deeper dive revealed that there were no providers of Independent Living Supports in 11 out of 20 service areas. Only two providers in Southwestern Virginia offered Supported Living services (Figure 7), and a deeper dive into the geographic disparities revealed that there were no Supported Living providers in 11 out of the 20 service areas. The limited number of providers limits an individual's choice and access to independent living.

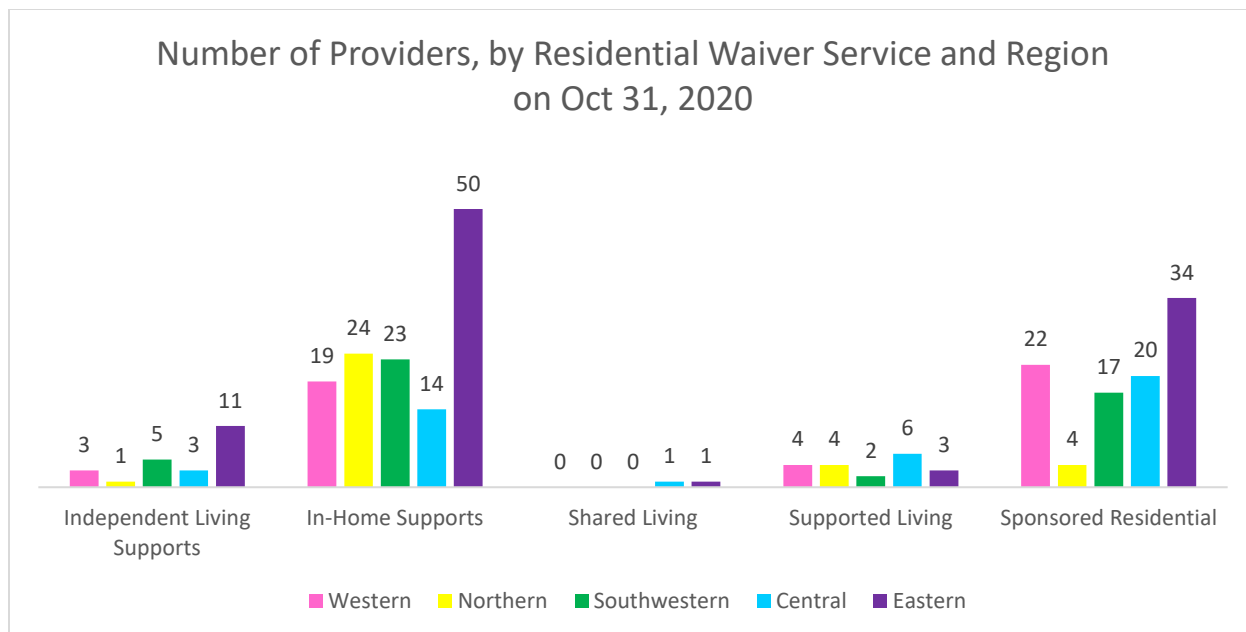


Figure 7: DBHDS Provider Data Summary, November 2020

The extent to which there is unmet demand for the new residential waiver services is unclear. In order for an individual to receive one of these new services, a participating provider must submit a service authorization to DBHDS on behalf of the individual in the waiver. Therefore, the low number of service authorizations may be reflective of the low number of service providers rather than a low demand for the service. Results from a VBPD survey of family members of people with disabilities indicate that this may be the case for at least some people. Five out of 12 (41 percent) survey respondents reported that a lack of providers in their area “moderately” or “significantly” contributed to their inability to access independent living options. Consequently, it is difficult to assess how many more individuals would seek service authorizations if more providers were available.

Opportunities to Expand Supported Living

Stakeholders Perceive Several Barriers to Supported Living

In interviews with self-advocates, providers and advocacy group representatives, participants discussed barriers to the further growth and development of Supported Living services in Virginia. The key themes of adequate rate structure, perception about service, and confusion about terminology and licensing requirements emerged.

Rates

The rate structure for this service does not adequately cover provider cost to deliver this service. In addition, the rate structure does not sufficiently incentivize providers to develop Supported Living services as part of their business model and service array.

Perception That Service Only Supports Individuals with Fewer Support Needs

There's a perception among some providers that Supported Living is only appropriate for individuals with minimal support needs. This perception translates to a belief that individuals with more complex support needs, including medical and behavioral supports, are not a good "fit" for this service. Similarly, self-advocates reported in VBPD focus groups that they were concerned that they would not be able to get 24 hour/7 day a week support if they moved out of their current group home. Additionally, three focus group participants who currently lived independently or in Supported Living apartments said that they had challenges getting the amount and frequency of one-on-one supports needed to consistently assist them.

Confusion Over Terminology

There is confusion among individuals, providers, and support coordinators about many aspects of the Supported Living service. Some individuals living in their own apartment believe they are receiving Supported Living services when they are actually receiving a combination of other waiver services such as in-home and personal assistance services. Some individuals and families may not understand that Supported Living services are provided in a provider-owned/operated setting. This means that if the individual decides to switch providers, they must also move out of the Supported Living apartment/home. One advocate summarized the connection between service and housing as, "You lose one, you lose the other." It was also reported that this service is not described and explained using consistent terminology by support coordinators, which can be a reason for the confusion.

Confusion Over Licensing Requirements

In interviews, providers and advocates disagreed on whether the Supported Living setting must be licensed by DBHDS. In the same interviews, providers stated that DBHDS requires licensing of all Supported Living apartments, whether they are leased by the provider or individual themselves. This confusion stems from a lack of clarity in the final waiver regulations, which state in one subsection that "the provider shall be licensed by DBHDS..." but later references "DBHDS licensed settings" in the same subsection (12 VAC 30-122-540(D) (1) and 12 VAC 30-122-540(D)(5)). This lack of clarity, in turn, has led to misinformation and reported inconsistency among licensing specialists.

Recommendations to Expand Supported Living

Recommendation 1: The General Assembly should support the goals of the Settlement Agreement and waiver redesign to incentivize integrated and independent living options by establishing rates for the provision of supported living services that are comparable to the rates for the provision of group home residential services.

Recommendation 2: The Department of Behavioral Health and Developmental Services (DBHDS) should resolve inconsistent practices among licensing specialists when licensing Supported Living to ensure it is the provider that requires licensure, rather than the apartment/home being a DBHDS licensed setting.

Recommendation 3: DMAS should clarify and resolve conflicting information in the waiver regulations located at 12VAC30-122-540, which states that the supported living “provider shall be licensed” but also describes supported living services being provided in a “DBHDS licensed settings.”

Recommendation 4: DBHDS and Community Services Boards should ensure that support coordinators have a comprehensive understanding of supported living services, including the differences between supported living and in-home supports. Support coordinators must be knowledgeable and accurate when explaining to individuals and families the various service options and opportunities available in the DD waivers, including supported living services.

Opportunities to Expand Independent Living Supports

Stakeholders Perceive Several Barriers to Independent Living Supports

In interviews with self-advocates, providers, and advocacy group representatives, participants discussed barriers to the further growth and development of Independent Living Services (ILS) in Virginia. The key themes of the design of the BI waiver, need for Personal Assistance Services (PAS), and lack of service planning flexibility emerged.

BI Waiver Design

All services available in the BI waiver are available in the CL and FIS waivers except ILS. One stakeholder interviewed stated that this means “an entire DD waiver is being administered and operated for one service, ILS.”

ILS is an Incomplete Standalone Service

ILS is only available to people using the Building Independence (BI) waiver. BI is also the only waiver that does not include Personal Assistance Services (PAS), despite advocacy for PAS inclusion during waiver redesign. Without access to PAS, providers and advocates believe that people who may need occasional or ongoing support with Activities of Daily Living (ADLs) do not view the BI waiver as a viable option. People who would like to use ILS to work on independent living skill building may need PAS to make their independent living situation sustainable. Consequently, many people on the Priority One waitlist offered a BI waiver slot turn it down and continue to wait for a CL or FIS slot. If there are no individuals on the Priority One waitlist willing to accept a BI waiver slot, a regional Waiver Slot Assignment Committee session is held to assign the BI waiver slot(s) to individuals meeting criteria from Priority Two and then Priority Three waitlists. Ultimately, the low usage of this service is due in part to the BI waiver’s inability to serve the needs of eligible individuals who need PAS.

Lack of Service Planning Flexibility

There is a perceived lack of flexibility in how individualized services can be planned based on the number of weekly support hours built into the ILS rate model. For example, individuals on the BI waiver in support needs level one may typically receive 14 hours of independent living supports per week. Individuals in support needs levels two through four may typically receive

21 hours of independent living supports per week. There is uncertainty about the ability to develop a Plan for Supports with, for example, 11 hours of supports one week and 31 hours of supports another week based on individual need and preference versus a prescribed weekly number of hours, especially with a service that is billed monthly with a monthly reimbursement rate. Due to this lack of flexibility, providers are concerned about being able to provide individualized supports that match the varying needs and changing circumstances of the individuals served.

Recommendations to Expand Independent Living Supports

Recommendation 5: The Department of Medical Assistance Services should add the Independent Living Supports service to the Family and Individual Supports (FIS) waiver. All individuals on the Building Independence (BI) waiver should seamlessly transition to the FIS waiver, and the BI waiver should be eliminated.

Opportunities to Expand Shared Living

The Shared Living service has been rarely utilized, as discussed earlier in this report, despite having some unique qualities that should facilitate quick adoption. Since the service began in 2017, only two providers have offered this service and only three people have used it. Yet, Shared Living is the only residential service available across all three waivers and there are minimal requirements to become a provider.

To be a Shared Living administrative provider, providers must only be licensed by DBHDS to provide services to individuals with DD. This allows providers who are already licensed by DBHDS, such as sponsored residential, group home, group day, and in-home services providers, to readily enroll with DMAS to be an administrative provider of Shared Living. This means that a large number of eligible provider organizations are choosing to not enroll with DMAS as an administrative provider of this service.

Stakeholders Perceive Several Barriers to Shared Living

In interviews with providers and advocates, participants discussed barriers to the further growth and development of Shared Living services in Virginia. The following key barriers were identified:

Lack of Awareness About the Service Design

Some of the stakeholders interviewed were surprised to learn that it is allowable for the Shared Living roommate to be a family member, as long as they are not a parent, grandparent, guardian or spouse. For example, a sibling or cousin could be a roommate. While the service also anticipates roommate-matching, Shared Living can be a way to promote natural supports, such as family or friends. Further, some stakeholders were unaware that a person can live in their own apartment with a roommate using the Shared Living service, and still receive other services in their home (e.g., in-home, personal assistance, or independent living supports if on the BI waiver).

Shared Living is a New Service With a Steep Learning Curve

Most new services offered through the DD waivers are similar to services that were offered before the waivers were redesigned. Shared living is the only residential service that is a new form of service delivery in which the provider offers administrative services rather than direct services. Providers may be hesitant to invest the time needed to learn about this new service model and expand their business model accordingly, resulting in fewer enrolled providers.

Limited Awareness of Available Transition Supports

Just as Shared Living is a new service model for providers, it is also a new form of independent living for individuals on the waiver. To prepare for living in their own home or apartment with a roommate, an individual may need transition services and supports. The need may be greater if the individual and roommate do not know each other well. The extent of needed transition services and supports may vary from individual to individual. Stakeholders interviewed were concerned about the lack of transition supports and were seemingly unaware of DBHDS flexible funding for these transition supports. Currently, DBHDS allows \$326.50 reimbursement per month for a period of two months to the administrative provider for transition supports (Virginia Department of Behavioral Health & Developmental Services, 2019). According to DBHDS' *Shared Living Toolkit*, set-up tasks/activities for Shared Living services may include:

- Identifying an individual's roommate preferences;
- Advertising for and interviewing roommates, and performing background checks on potential roommates;
- Arranging for required trainings for the roommate (e.g., CPR, safety awareness, fire safety and disaster planning, conflict management and resolution);
- Conducting a visual inspection of the housing unit;
- Facilitating discussions of expectations for supports between the individual and roommate;
- Assisting the individual and roommate with completion of the Supports Agreement form; and
- In addition, up to \$5,000 may be available to the individual to address barriers in obtaining housing, such as temporary support staffing, moving expenses and household furnishings.

Insufficient Rates to Incentivize Service

The administrative rate for the provider is currently \$101.27 per month (\$122.97 in Northern Virginia). This rate does not support the cost to the provider to effectively administer the service. As shared by one of the interview participants, provider agencies are businesses, and providers cannot afford to lose money when providing services. Current administrative responsibilities include (12VAC30-122-510) roommate matching as needed, background checks, training, periodic onsite monitoring, disbursing funds to the individual, coordinating the Shared Living service, submitting claims directly to DMAS for reimbursement, and maintaining required documentation of rent, roommate agreements, training, and face-to-face contacts.

Liability Without the Ability to Mitigate Risk

The service is structured so that the roommate is selected by the individual, and the roommate is not an employee of the provider. Yet, the provider remains responsible for ensuring services are delivered and the required documentation is maintained, or they risk payback/recovery by DMAS or its designee as a result of utilization reviews or audits. Should payback/recovery be required, it is unclear to the provider if the recovery will include the portion of the cost of rent, food and utilities that the provider submitted to DMAS for reimbursement to the individual or just the administrative fee reimbursed to the provider. This exposes the provider to financial liabilities they cannot control. As businesses, few providers are willing to take on that risk, especially with an inadequate administrative rate for providing this service.

Recommendations to Expand Shared Living

Recommendation 6: The Department of Behavioral Health and Developmental Services (DBHDS) should develop engaging vignettes of individuals with disabilities participating in shared living. Vignettes should represent different shared living situations and the additional services and supports an individual receives. Vignettes can depict different roommate situations (e.g., sibling, friend, matched roommate), differences in how people spend their days and evenings, and the use of assistive technology and electronic home-based supports to facilitate greater independence. The vignettes should be added to the Shared Living Toolkit and shared broadly with support coordinators, providers, individuals and families.

Recommendation 7: The Department of Medical Assistance Services (DMAS) and DBHDS should include the monthly reimbursement rate for the administrative provider of shared living services in the review of payment rates for services provided in the DD waivers currently required to be submitted to the General Assembly by November 1, 2021 (HB 1800, Item 320 #9C) and ensure that the rate assumptions accurately reflect service delivery design and cost.

Recommendation 8: DBHDS should implement a pilot project with providers interested in becoming an administrative provider of shared living services. These providers should receive training and technical assistance as they move through the process of supporting individuals to transition to shared living and providing the administrative services. There should be a strong research and evaluation component to the pilot project to: 1) identify and address barriers and 2) identify needed modifications and innovations to policy and practice to ultimately increase provider capacity and service utilization. DMAS and DBHDS should directly address provider concerns about their exposure to risk and liability based on the responsibilities and expectations of the administrative Shared Living provider outlined in regulations. Incentives should be provided to participating providers to reimburse them for their time and expertise.

Opportunities to Expand Assistive Technology, Environmental Modifications, Electronic Home-Based Supports, and Other Services

Three key DD waiver services that provide individuals receiving services with greater autonomy and independence. The services include the following:

- **Assistive Technology:** specialized medical equipment, supplies, devices, controls, and appliances, not covered by insurance which enables individuals to increase their independence in their environment and community.
- **Environmental Modifications:** physical adaptations to the individual's primary home or primary vehicle that are necessary to ensure the health and welfare of the individual or enable the individual to function with greater independence.
- **Electronic Home-Based Services:** goods and services based on smart home technology that can be used in the individual's residence to support greater independence and self-determination. This includes purchases of electronic devices, software, services, and supplies not otherwise provided through the DD waivers or through insurance. In the peer-led focus groups, self-advocates shared information about innovative uses of various technologies and supports that add to their independence, sense of security, and overall well-being. For example, participants reported benefiting from biometric or keypad locks, vibrating alarm clocks, stovetop guards that automatically turn the stove off, "smart assistants" like Alexa, and smoke alarms that can provide instructions using the participant's mom's voice.

These services are often not used to their maximum benefit for several reasons. Barriers include complexities of service authorization and access, as well as a lack of provider capacity. In some cases, service funding caps are not sufficient to cover the cost of a specific technology or home modification. All three services are currently capped at \$5,000 each.

The service caps are effectively lower when individuals use particular providers who charge a large administrative fee. For example, some Assistive Technology providers have administrative fees as high as \$1,500, effectively reducing the actual \$5,000 benefit to the individual to \$3,500. Individuals and their families know what will best meet their needs and are capable of procuring the needed technology or modification without a middleman acting as a "broker."

The services could have a greater impact by combining their individual spending caps of \$5,000 to a pooled cap of \$15,000, given that all waiver recipients are eligible for all three services. The total allocated to the services would not change, but an individual would be able to afford necessary but costly environmental modifications or assistive technology to enhance their quality of life, independent living, and autonomy in the community.

Self-Advocates Need More Assistance With Financial Literacy

Several participants who lived independently said they needed to learn budgeting skills as part of living on their own. Making a budget and figuring out how much money they had every month was a new and important task for people who had previously lived with their family or in a group home.

Current service options do not sufficiently address this need. The DD Waivers currently offer Benefits Planning, which helps people understand their federal and state benefits. However, the service does not comprehensively address personal finance or household budgeting.

Recommendations to Enhance Services That Facilitate Greater Autonomy, Independence, Safety, and Security

Recommendation 9: The Department of Medical Assistance Services (DMAS) should explore options to provide Assistive Technology, Environmental Modifications and Electronic Home-Based Supports as a Consumer Directed Service.

Recommendation 10: DMAS should allow the \$5,000 cap on Assistive Technology, the \$5,000 cap on Environmental Modifications, and the \$5,000 cap on Electronic Home-Based Supports to be a combined \$15,000 cap across all of these services. DMAS should seek the approval of the General Assembly if needed. This will increase an individual's ability to purchase necessary but expensive services, without increasing the total cost allocation for services.

Recommendation 11: DMAS should make financial literacy training an allowable activity for transition planning services or as part of the benefits planning service.

Opportunities to Empower Individuals: There is a Need to Strengthen the Voice of Self-Advocates Within the Disability Services System

In peer to peer focus groups, individuals with disabilities expressed the importance of not only being listened to, but being heard. The system of services and supports they rely on does not often embrace the voices and choices of self-advocates. Individuals and families experience service planning discussions that lack depth and a sincere interest in supporting individual choice. All of the self-advocates interviewed who now live independently accessed resources because of their self-advocacy and/or the advocacy of their family members.

The experience and expertise of self-advocates, who have the greatest investment in the system of services and supports on which they depend, are often missing from critical decision-making and opportunities to educate decision makers. If self-advocates had a more formal role in the disability service system, they would amplify the perspectives of individuals using waiver services and could help others with DD brainstorm solutions to barriers in living independently. Paid self-advocate advisors could also educate families and support coordinators about the importance of individual preference and share creative ways to achieve outcomes, based on their personal experience.

DBHDS has already made advances in incorporating self-advocates through the Peer Mentor Service. Through the Peer Mentor Service, an experienced, trained peer mentor is paid to provide information, resources, guidance, and support to an individual receiving waiver supports. Peer mentors are individuals with developmental disabilities who are or have received services, have shared experiences with the individual, and provide support and guidance to him/her. The service is designed to foster connections and relationships which build individual resilience (12VAC30-122-450). Unfortunately, the Peer Mentor service has been underutilized. As of April 2020, no individuals had been authorized yet for this service. Several

participants in VBPD focus groups said they were eager to serve as a Peer Mentor help other individuals prepare to live on their own.

While Peer Mentors are a promising way to help build individual competency, individuals with DD in paid positions will help build the competency of the service delivery system itself. For example, the Connecticut Department of Developmental Services has ten part-time state employees in the role of Self Advocate Coordinators who are responsible for “expanding and enhancing self-advocacy in Connecticut, representing consumer viewpoints on agency committees and workgroups, encouraging consumers to have more influence in policy development, enhancing the training provided by the department from a consumer’s perspective [and] creating materials written for, and by, people with developmental disabilities” (The State of Connecticut Departmental of Developmental Services Self Advocate Coordinators, 2007).

The Service System Must Ensure Meaningful Choice Through Person-Centered Planning

Choosing an independent living option requires individuals with DD and their families to make many related choices about where the person will live and how they will be supported in their own home. The myriad of choices are one way in which independent living promotes autonomy and satisfaction. However, more choice also requires more knowledge about the different options and how to access them.

Person-centered planning is an important tool for helping people with DD and their families identify choices that are right for them. Person-centered planning is defined in the waiver regulations as “a fundamental process that focuses on what is important to and for an individual and the needs and preferences of the individual to create an individual support plan” (12VAC30-122-20). A review of state definitions found that person-centered planning requires “focus on the person, an understanding of the importance of choice and self-determination, and a commitment to full inclusion and access to the community” (Lawrence, 2020).

Based on feedback from individuals, families, and stakeholders, there is lack of creativity and flexibility in developing individual support plans that reflect the array of service options designed to better support meaningful inclusion in all aspects of community life. Some individuals and families express a high regard for their support coordinators who are always available to answer questions and open to out of the box thinking and service options. Others report a different experience including unreturned phone calls, preconceived notions about competence and abilities, and more concern over paperwork and process than for what’s important to the individual. On a VBPD survey of family members of people with disabilities, only 25 of 44 respondents (57 percent) agreed with this statement: *“I have had a positive experience getting the information I need about available DD waiver services.”* 11 percent were neutral, and 32 percent disagreed.

The Independent Reviewer has repeatedly found deficiencies in Virginia’s Case Management system and cites it as an obstacle to accessing independent living options (Fletcher D., 2019). In June 2019, the Independent Reviewer observed, “An effective Case Management system, which is critical for coordinating services for a successful independent community housing program, would include effective long-range planning, specific and measurable goals and objectives that will increase integration and self-sufficiency, and routinely implemented protocols that determine the appropriateness of current services.” (Fletcher D., 2019).

While DBHDS has made strides in training support coordinators in residential options and person-centered planning, planning for independent living requires both knowledge and creativity. Researchers have noted that training may result in knowledge of the technical planning steps “without full understanding of the philosophical foundation of person-centered thinking” (Barth, Lewis, & Simmons, 2020).

While the Board recognizes that support coordinators have many responsibilities, responsive person-centered planning that addresses individual preferences, goals, and barriers is essential to ensuring an individual can choose freely. A review for the Medicaid and CHIP Payment and Access Commission found that:

Stakeholders emphasized the importance of ensuring the rights and preferences of the person with ID/DD are asserted and protected in the planning and delivery of services and supports. Several stakeholders shared that for many people with ID/DD, exercising choice and self-determination requires that they get assistance in understanding complex information and developing needed skills to advocate for their own preferences and decisions (Barth, Lewis, & Simmons, 2020)

One way to improve person-centered planning is to offer it as a separate service under the waiver. A 2020 review found that five states offered a “Person-Centered Plan Facilitation Service” (separate and distinct from case management) through HCBS waivers. The study defined “Person-Centered Plan facilitation” as “supplemental support (which can occur before, during, or after the annual plan) to ensure that what occurs during the annual service planning process and implementation aligns with person-centered practices.” The services focus on things like education to develop self-advocacy skills to exercise control and responsibility over the supports that the person receives. Providers of the service are required to receive training in nationally recognized person-centered planning methods or state-approved person-centered training (Kardell, 2020).

Recommendations to Further Individual Empowerment in the DD Services System

Recommendation A: The Department of Behavioral Health and Developmental Services (DBHDS) should incentivize CSBs, possibly through a pilot project, to incorporate self-advocates

in paid positions to bring perspective and experience to the training of support coordinators, including adding a self-advocate-led module in the required support coordinator training modules. The self-advocates can provide guidance through lived experience on the education of individuals and families about services and supports and advise on the principles of person-centered planning and individualized supports. *(Recommendation also included in the day/employment services assessment).*

Recommendation B: The Department of Medical Assistance Services (DMAS) should consider establishing and seeking General Assembly approval of person-centered facilitation as a distinct, non-duplicative waiver service that would provide more support and expertise to tailor service options to an individual's needs and goals like in Kentucky, where "person-centered coaching" services provide "for modeling, monitoring, assessing and implementing the person-centered plan. *(Recommendation also included in the day/employment services assessment).*

Assessment of Day and Employment Services available in the DD waivers

Landscape: Options and Trends in Services

This assessment addresses the redesigned Day and Employment services that were added to Virginia's Developmental Disability waivers with the aim of providing more integrated service options. True community integration includes the opportunity to contribute in the community, join the workforce alongside people without disabilities, and earn a competitive wage. This type of work environment is typically referred to as competitive, integrated employment. The assessment will first discuss integrated employment overall, including its importance and prevalence, and then evaluate the extent to which the new services have furthered meaningful work and community day activities in Virginia.

The Value of Integrated Employment: From Sheltered Workshops to Competitive Employment and Community-Based Day Services

The Benefits of Integrated Employment for People With Disabilities

Integrated employment offers physical and mental benefits for everyone, including people with DD. Research has consistently demonstrated that paid community employment leads to better health outcomes; minimizes the harmful physical, mental and social effects of long-term unemployment; promotes full participation in society, independence and human rights; reduces poverty; and improves quality of life and well-being (Waddell, 2006). Additionally, VBPD focus groups with Virginians with DD revealed high job satisfaction among those who worked.

Research has also shown that working in the community has a positive effect on the wellbeing of an individual with DD. In a national survey, people with community jobs reported having a greater quality of life compared to those not working in community jobs. People with community jobs also scored higher in outcomes such as satisfaction with where they live, having friends, making everyday choices and having their rights respected (National Core Indicators, December 2011).

Self-Advocates Value Employment Opportunities

In peer-led focus groups of adults using waiver services, participants who were employed expressed a high level of satisfaction with their jobs.⁵ All the individuals interviewed who were employed said they enjoyed working. Several participants had jobs with the same company for many years. Others had to try several jobs before they found one that was a match for their interests and skills.

⁵ See Appendix A for a description of focus group participants.

A responsive job coach was critical to many people's satisfaction with their jobs. Focus group participants talked about the importance of a job coach in helping them find a job that matched their interests and skills. One participant's job coach matched him with his "dream job," using his interest in athletics to connect him with a job at a university athletic center. Another participant found a successful match for her interests and skills on her third job placement.

Yet, several participants had disappointing experiences with job coaches. One participant who needs personal assistance was told by her job coach that she would need to "work on [her] independent living skills," before she could get a job. The Job Coach ultimately did not help her with a placement and the individual never got a job.

While employed participants uniformly enjoyed their jobs, benefits remain a barrier for participants who would like to increase their hours worked or seek employment. Several participants said they were interested in working more hours, but participants voiced concern that they would lose access to their DD waiver, Supplemental Security Income, or other benefits if they earned too much income.

People With Disabilities Have Had Limited Access to Integrated Employment Settings

Traditionally, people with disabilities have lacked meaningful opportunities to gain employment and participate in the community, due in part to the false assumptions of disability service systems. For decades, people with developmental disabilities (DD) were not offered services to support them in competitive, integrated jobs. Instead, Medicaid-funded systems placed people in segregated day services and sheltered workshops.

That trend continues today. In its *2020 Progress Report on National Disability Policy: Increasing Disability Employment*, the National Council on Disability found that "In 2020, the vast majority of Medicaid-funded employment services continue to be provided in segregated settings, where people with disabilities typically perform rote, repetitive manual tasks with only other people with disabilities under the supervision of paid support staff (i.e., sheltered workshops), rather than in competitive integrated employment." (National Council on Disability (NCD), 2020).

In 2019, 19.3 percent of people with disabilities were employed nationwide, in contrast to 66.3 percent of people without disabilities (National Council on Disability (NCD), 2020). Similarly, in Virginia in June 2020, the employment rate was 19 percent for adults ages 18-64 receiving DD waiver services or on the waitlist. This rate is below the Commonwealth's goal of 25 percent (Fletcher, D., 2020)

Integrated Day and Employment services are part of the Settlement Agreement. Figure 8 shows some key targets for compliance with the Agreement Based on reports of the Independent Reviewer, the Commonwealth still lags behind for each of the indicators listed.

Compliance Indicator	Status as of June 2020	Compliance Status
25% employment for adults ages 18-64 receiving DD waiver services or on the waitlist.	19 percent	Not Met
50% of adult's ages 18-64 receiving DD waiver services have employment as a goal in their ISP.	30 percent	Not Met
86% of adults ages 18-64 receiving DD waiver services have community engagement goals in their ISP.	38 percent	Not Met

Figure 8: Data from Report of the Independent Reviewer, U.S. v. Virginia, December 15, 2020

Virginia Has Made Several Efforts to Increase Integrated Day and Employment Opportunities

Despite the low employment rates and persistence of segregated settings, many DD waiver services support meaningful work and day activities in the community. As discussed earlier in the “Background” section, the Commonwealth now offers Day and Employment services that support individuals to pursue their interests for community involvement, recreation, volunteering and employment. These new services respond to the growing expectation of individuals with DD that they will work alongside people without disabilities and earn a competitive paycheck. Today, most youth with disabilities “definitely expect to work” following completion of their education (National Council on Disability (NCD), 2020). Virginia’s current Day and Employment services are a mix of services that existed before the waiver redesign in 2016 and services that were added during the redesign. Individual Supported Employment and Group Supported Employment were offered both before and after the waiver redesign. New services include Community Engagement, Community Guide and Community Coaching. Figure 9 provides a description of each service and the waiver in which the service is available.

Employment and Day Services	BI	FIS	CL	Description
Individual Supported Employment	✓	✓	✓	Individual Supported Employment services are provided one-on-one by a job coach to an individual in an integrated employment or self-employment situation at or above minimum wage in a job that meets personal and career goals.
Group Supported Employment	✓	✓	✓	Group Supported Employment services are continuous support provided in regular business, industry and community settings to groups of two to eight individuals with disabilities. These services involve interactions with the public and with co-workers without disabilities.
Workplace Assistance Services		✓	✓	Workplace Assistance services are provided to someone who has completed job development and completed or nearly completed job placement training but requires more than typical job coach services to maintain stabilization in their employment. Workplace Assistance services are supplementary to job coach services; the job coach still provides professional oversight and coaching.
Community Engagement	✓	✓	✓	Community Engagement Services are provided in groups of no more than one staff to three individuals. Community Engagement fosters the ability of the individual to acquire, retain, or improve skills necessary to build positive social behavior, interpersonal competence, greater independence, employability and personal choice necessary to access typical activities in community life such as those chosen by the general population. Activities may include community education or training, retirement, and volunteering.
Community Guide	✓	✓	✓	Community Guide is a service to assist an individual with determining specific preferred activities and venues that are available in the individual's community with which the individual desires to connect (e.g. clubs, special interest groups, physical activities/sports teams, etc.). The service promotes inclusion and independent participation in the life of the individual's community. There are two types of community guide services: one for general community guide activities, and one to help individuals access independent housing. This section of the assessment focuses on general community guides.
Community Coaching	✓	✓	✓	Community Coaching is a service designed for individuals who need one-to-one support in order build a specific skill or set of skills to address a particular barrier(s) preventing a person from participating in activities of Community Engagement.

Figure 9: Definitions of Day and Employment Services

Trends in Use of Employment and Day Services

More People Have Been Utilizing Individual Supported Employment Services to Obtain and Maintain Employment, While Use of Group Supported Employment Has Declined

Following the waiver redesign, more people have utilized individual but not group supported employment. The number of Virginians who utilized individual supported employment (ISE), has increased 312 percent since 2012 (Figure 10). Most of this increase occurred after the waiver was redesigned in 2016. Meanwhile, the number of Virginians who utilized group supported employment (GSE) has decreased 21 percent since 2012. Most of this decline occurred after the waiver was redesigned in 2016.

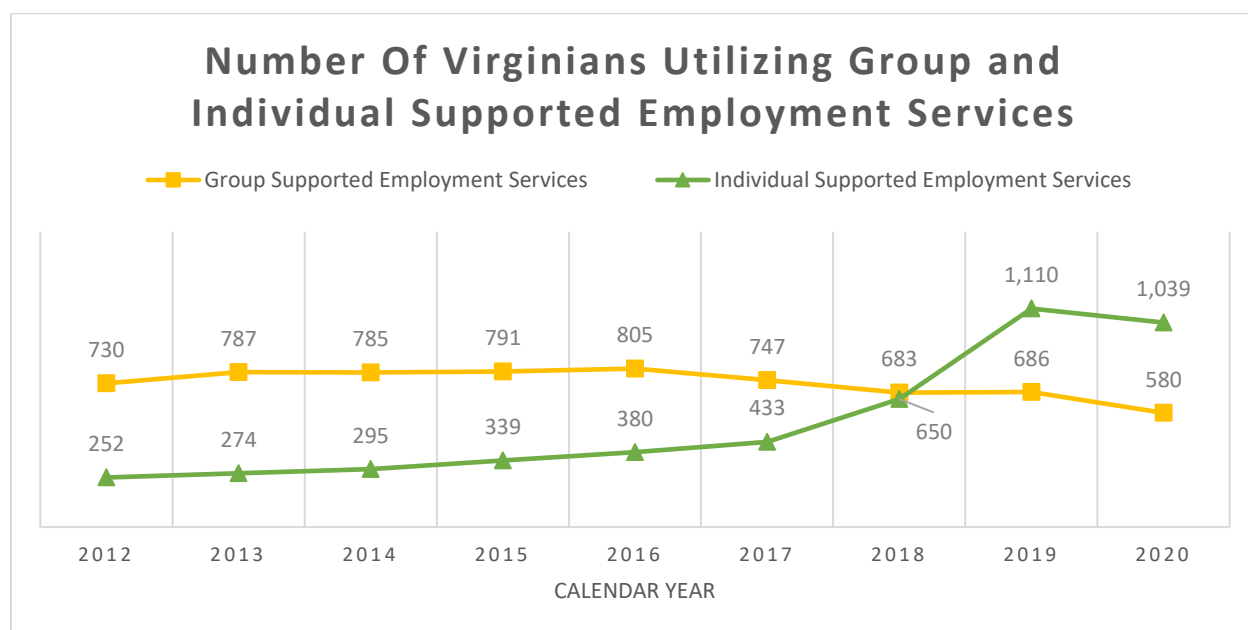


Figure 10: Unduplicated service utilization member count based on claims data by calendar year (Department of Medical Assistance Services)

GSE and ISE services also include job search support, so a portion of the people using these services are not yet employed at any given time. In June 2020, 84 percent using ISE services were employed, compared to 75 percent in June 2019 and 73 percent in June 2018 (Fletcher D., 2020).

Few People Have Utilized New Workplace Assistance Services, but Utilization Has Grown

Workplace Assistance is a new service available in the FIS and CL waivers. This service offers up to 40 hours of supports per week for individuals who need additional supports other than typical job coach supports to maintain individual, competitive employment. This service does

not include work skills training normally provided by a job coach. It does include supports to assist with health management, time management, social skills and relationships with co-workers, and personal assistance (it cannot be exclusively used for personal assistance). Utilization of Workplace Assistance increased shortly following waiver redesign, but the rate of growth has slowed in recent years. The number of people using Workplace Assistance services increased from one person in 2016, when the waiver service was first offered, to at least 80 people each year from 2018 through 2020, according to unduplicated service utilization member count data provided by DMAS.

Use of New Day Services Has Increased, but Remains Substantially Lower Than Less Integrated Options

Utilization of the Community Engagement service increased substantially after it was introduced in 2016, but growth slowed and then reversed in recent years. The number of people using the service Community Engagement, which supports individual involvement in recreation and volunteer activities, increased substantially, from no service recipients in 2016 to 2,887 service recipients in 2018. The number continued to grow between 2018 and 2019, albeit at a slower rate of growth, reaching 3,165 people in 2019. However, the number of service recipients declined in 2020 to a level that was similar to that of 2018 (Figure 11), even though waiver enrollment increased by about 13 percent during that time period. The decline in service utilization may be due in part to the COVID-19 pandemic, which limited opportunities for community engagement.

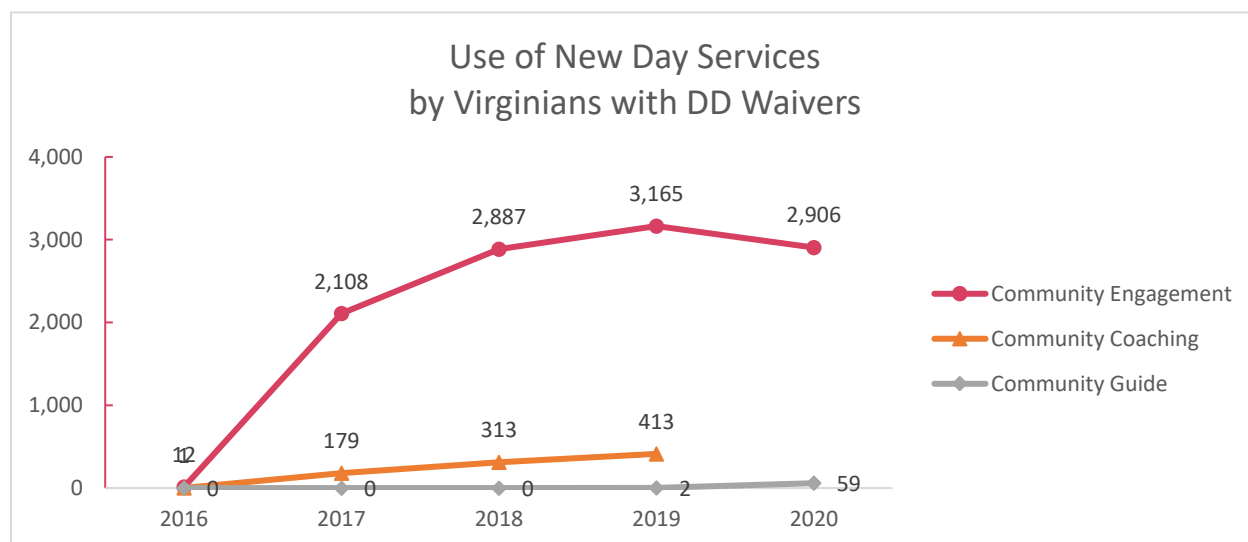


Figure 11: Unduplicated service utilization member count based on claims data by calendar year (Department of Medical Assistance Services). Utilization Data not available for Community Coaching in 2020.

Utilization of the Community Coaching service has also grown since it was first introduced in 2016, albeit at a slower rate than Community Engagement. Community Coaching is a one-on-one service to help individuals develop skills that they need for community engagement. The

number of people who used the service grew from no service recipients in 2016 to 413 service recipients in 2019 (Figure 11). No data was available in 2020. While this service might be expected to have lower utilization than the other services, because it provides a higher intensity of services for those who need it, there may be additional people who could benefit from it who are not currently using it.

While use of Community Engagement and Community Coaching services have grown, their use continues to lag far behind that of the less integrated day service called Group Day. In most regions of the Commonwealth in 2020, the number of individuals authorized for Group Day services was more than double those authorized for Community Engagement and Community Coaching services (Figure 12). Additionally, there are many people who are eligible for but do not receive day services, according to this data. Individuals who do not use Day services likely stay at home or volunteer during the day, based on a VBPD survey of family members of people with DD. Overall, this data indicates that opportunities exist for further development of the new Day waiver services.

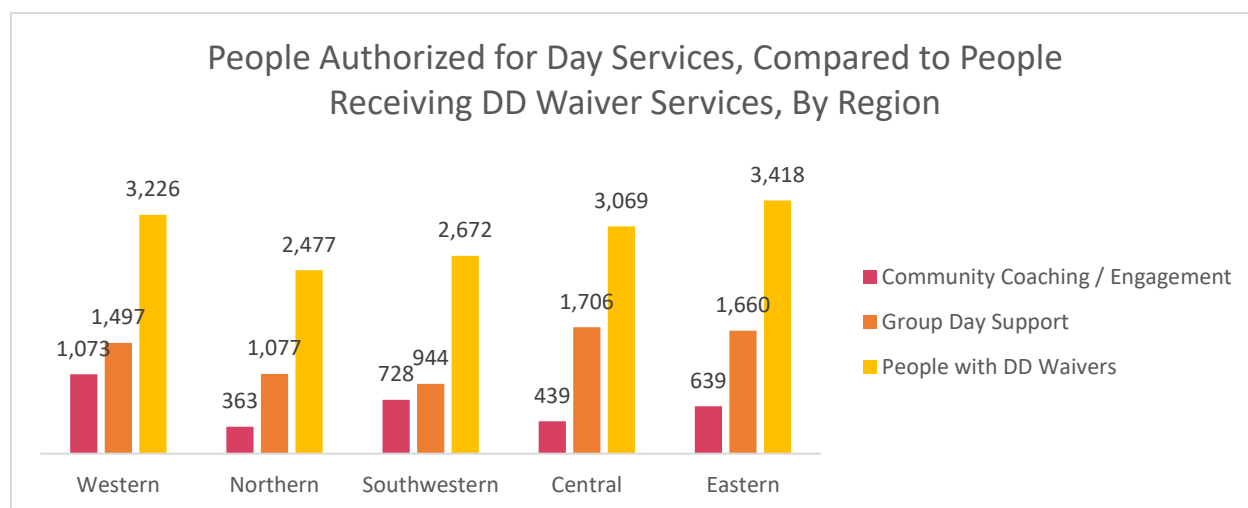


Figure 12: DBHDS Provider Data Summary, November 2020

In addition, the number of providers for both Community Engagement and Community Coaching remains very low compared to individuals eligible for the services in each region (Figure 13), although the service capacity of these providers is unknown. The Independent Reviewer has also noted that the lack of providers, particularly in rural areas, is a systemic barrier to participation in Community Engagement Services.

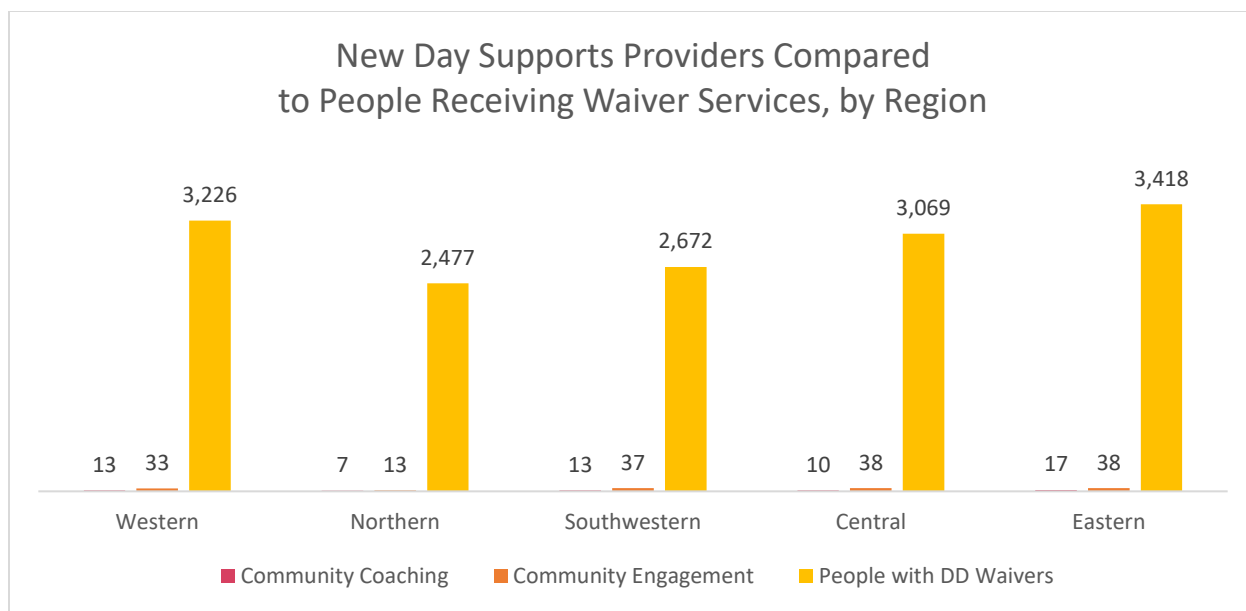


Figure 13: DBHDS Provider Data Summary, November 2020

It is too early to identify utilization trends for the Community Guide service, which was not implemented until 2019. Two people used this service in 2019 and 59 in 2020 (Figure 11). It is unclear how many of these individuals used this service for general Community Guide activities, which are the focus of this assessment, or Housing Guide activities. Regardless, continued growth of provider capacity and utilization would further the goals of waiver redesign. This service offers an exciting opportunity to connect individuals to a variety of community activities and resources that are of interest to them.

Opportunities to Expand Supported Employment

Feedback from self-advocates, family members, providers, and other stakeholders shows that the supported employment service is in need of an overall culture change. Navigating a web of processes to access supported employment services and gain employment is confusing to support coordinators, people with disabilities, and families. There's a deep knowledge gap that ultimately results in no employment outcomes for individuals. Barriers to employment are often unaddressed, particularly for individuals with more support needs. People with disabilities can wait six months or longer to be found eligible for supported employment services through the DD waivers. There is a need for creativity and innovation, training on the fundamentals of disability employment and accountability for successful employment outcomes.

Employment Goals Are Not Fully Explored

The provision of employment services is dependent on the development and pursuit of an individual service plan that identifies employment as a goal. Discussions about employment are a key way in which individuals using waiver services can decide if they want to work and discuss what kind of job supports they need. However, information indicates that these discussions do

not always occur and are not always effective when they do occur, which likely contributes to the low percentage of individuals expressing interest in employment.

Educating individuals about the benefits of employment is part of the Commonwealth's Employment First policy. A review by the Expert Consultant of the Independent Reviewer found that, of 62 individuals deemed able to work but not interested in employment, only nine received education about employment (Fletcher D., 2020). Similarly, ten (31 percent) of 32 family members of people receiving DD Waivers, who responded to a VBPD survey, said employment had not been discussed during the annual ISP meeting in the past two years.

When employment is discussed, employment goal-setting is often not exploratory or affirming of individual's skills and desires, according to VBPD interviews with providers and advocates. Instead, employment conversations are often cursory, "yes/no" discussions. To effectively discuss employment, the conversation needs to be more exploratory about a person's interests and supports available to make employment a reality.

This insufficient education likely contributes to the limited number of people with employment goals. Only 30 percent of eligible Individual Service Plans reviewed by the Independent Reviewer, as of June 2020, had an employment goal (Fletcher D., 2020). This was substantially lower than the Commonwealth's goal of 50 percent.

Employment Goals Are Not Fully Pursued Once Established

Even when individuals have employment goals, their preferences are not always pursued according to DBHDS Quality Service Reviews (Figure 14). In interviews with individuals receiving services, almost 40 percent said their preferences were actively addressed only "sometimes" or "rarely." In reviews of provider and support coordinator records, individual preferences were pursued only "sometimes" or "rarely" in 13 and 19 percent, respectively, of cases. Relatedly, employment barriers were not addressed for some individuals. Nearly 40 percent of individuals and providers reported that employment barriers were addressed only "sometimes" or "rarely." (Virginia Department of Behavioral Health & Developmental Services, 2019).

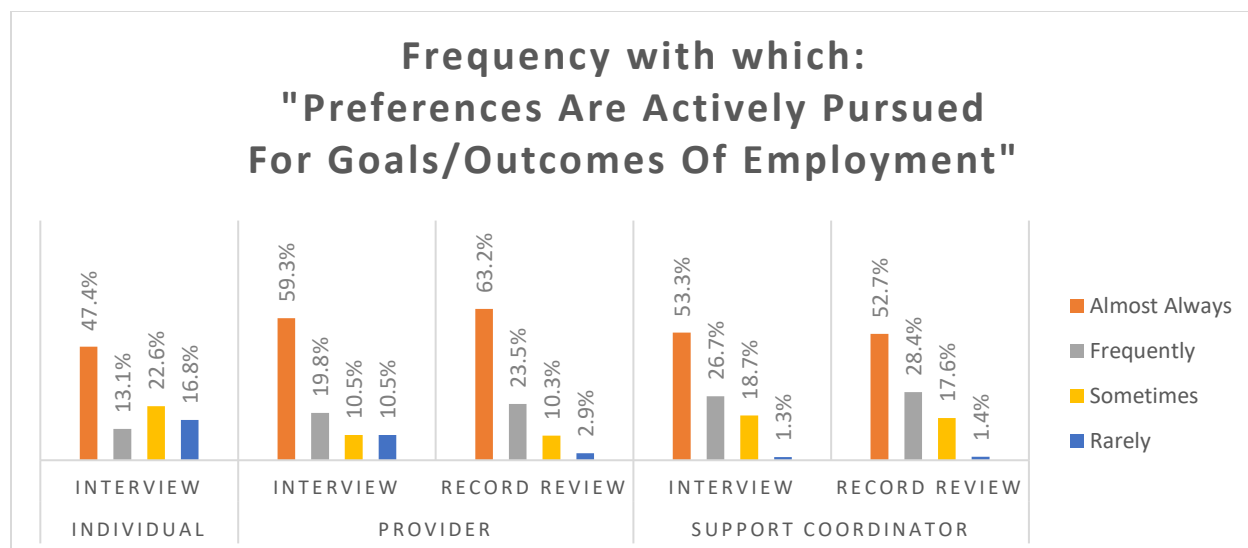


Figure 14: Virginia Quality Service Reviews: Year 4 Annual Report July 2018 – June 2019 (FY19)

Job coaching is often not tailored to the individual's interests and skills, according to a VBPD survey of family members of people with DD and focus groups with self-advocates. The majority of survey respondents who had unemployed family members listed "Unable to find a good match based on my family member's interests" as a significant factor in lack of employment. One respondent stated:

"Every time a new agency works with my daughter we have to start over with getting to know her and her interests. She worked with DARS for a year and her case was dropped because they could not find her a job. However, they did not seem interested in focusing on her interests instead they used their reliable employers to try various jobs out that we knew would not work."

Another family member shared the following: "We have not been successful in being able to explore customized employment and the job coach we used once did not have the needed skills to support my child and was very condescending."

Similarly, some self-advocates reported being disappointed with their job coach. One participant was told by her job coach that she would need to work on her independent living skills before she could get a job. The job coach did not help her with finding employment. This feedback indicates a need for more customized, tailored services to creatively pursue an individual's preferences.

Individuals With Higher Behavior and Medical Needs Lack Support for Employment

Both the lack of individuals with employment goals, and the significant percentage of employment barriers that go unaddressed, may be due in part to the misperception that supported employment is unworkable for those with significant behavioral or medical needs.

This misperception may be held by the person with a disability, their family members, their support staff, and employers. The misperception must be corrected in order for individuals of all support needs to successfully pursue employment, in line with Virginia's Employment First policy.

Support coordinator, in particular, are key to correcting this misperception, yet they are not adequately prepared to do so. In reviewing Case Manager Employment Training developed by DBHDS, the Expert Consultant of the Independent Reviewer noted that "The training does not equip the [case manager] to address questions or concerns families or individuals may have regarding complex disabilities. There is no information about behavioral or medical supports that may be available to individuals with these needs." (Fletcher D., 2020). Training about behavioral or medical supports was added in October 2020. This additional training may better prepare support coordinators to address barriers for more individuals, but it is too early to tell.

The lack of adequate training for support coordinators can perpetuate misperceptions among some individuals, resulting in individuals with higher support needs having less access to employment. For example, self-advocates said in VBPD focus groups that they are afraid of not having access to personal assistance services, which are critical for helping them use the restroom or eat or drink. One interviewee was told her need for assistance with activities of daily living would prevent her from having a job.

Nearly all family members who responded to a VBPD survey identified lack of training, and lack of support while on the job, as reasons why an individual with a disability was unemployed. These experiences support the perspective of disability advocates who point to the limited understanding of supported employment policy, practice, and expectations across the DD waiver services system and among critical partners.

Individuals with higher support needs who are able to obtain employment encounter difficulty obtaining needed supports in the workplace, according to VBPD interviews with disability service providers, advocates, and other key stakeholders. They also report that workplace assistance services are not always offered to those who need it.

For employment to be the first option for everyone, barriers to employment, including support issues and initial lack of interest, need to be addressed by support coordinators and providers so that individuals and their family members can see employment as a viable option. The Expert Consultant for the Independent Reviewer found that service planning discussions must include the "benefits of employment, the person's interests, skills, and challenges are discussed or that the plans developed address these issues, or that the [Case Manager] provides ongoing opportunity for the individual and family to learn more about employment or how providers or staff could help address barriers" (Fletcher D., 2020).

The Current Reimbursement System Does Not Incentivize Supporting Stable, Sustainable Employment

Supported employment services are reimbursed by Medicaid based on an hourly reimbursement rate. While this model is traditional, it incentivizes the provider to provide staff time rather than results. Providers who successfully support a person to participate in competitive integrated employment are currently not incentivized to sustain or increase the hours an individual works, because successful employment often involves phasing out job supports.

Other states have used a “value-based purchasing” structure to incentivize supporting individuals in competitive integrated employment. Value-based purchasing (VBP) is defined as “any activity a state Medicaid program undertakes to hold a provider or a managed care organization accountable for the costs and quality of care they provide or pay for.” (National Association of Medicaid Directors, 2017). In the context of Supported Employment, VBP rewards moving individuals toward full employment through increases in provider compensation if an individual’s hours worked increase. VBP in supported employment can also reward “fading,” or reducing staff hours as an individual gains more skills. The ultimate goal of VBP is to increase the number of individuals who are competitively employed by offering a sustainable way for agencies to make Individual Supported Employment their primary service line (Mills, 2018).

Tennessee realized better employment outcomes following the introduction of a VBP managed care model for supported employment. The state tied specific, tiered payments to key “deliverables,” such as creating a job plan that meets certain standards, or to expected outcomes, such as remaining on the job for a number of months. The payment model also incentivizes job coaches to appropriately reduce the hours of coaching required, while supporting continued employment, and provides higher reimbursements for beneficiaries with higher needs. Following these changes, the state has seen more people engaged in competitive, integrated employment, making higher wages and working more hours per week (Herman Soper & al., 2018).

Wisconsin has implemented a similar model with its largest managed care organization (MCO) providing employment services. When the MCO switched to a value-based purchasing model that offered tiered rates to account for individuals’ levels of support needs and phased rates to account for the individual’s time in employment, they reported 70.6 percent growth of the number of people employed in competitive integrated employment over a six-year period (Mills, 2018).

Both Tennessee and Wisconsin show the promise of funding supported employment through a value-based approach. Tiered and/or phased rates can be a way to ensure providers support individuals who need more support by receiving competitive compensation.

Concerns About Benefits Keep Many Individuals From Working

VBP focus groups with self-advocates, and discussions with other stakeholders, point to a lack of understanding by individuals, families, and support coordinators about the impact of paid employment on a person's Medicaid and Social Security benefits. Benefits are a major concern for self-advocates and family members. Their concern is often based on misinformation and/or fear about losing Medicaid and the vital services they depend on should their family member gain employment. Although related education is available through the waiver service known as Benefits Planning, this service is often not used and benefits counselors do not always understand the DD waivers.

These findings are echoed by the Independent Reviewer. The Independent Reviewer found that DBHDS has not yet met the basic training requirement to give individuals seeking employment "practical knowledge about the relationship of employment to continued Medicaid benefits." (Fletcher D., 2020). He recommended that "[Case Managers] need to be more prepared to have initial discussions about the impact of wages on existing Medicaid and other benefits, so families are more comfortable seeking more information about this critical issue rather than dismissing employment as even an option at the ISP meeting." By educating individuals and families about employment's impact on benefits, support coordinators can ensure that disinterest in employment is not based on misinformation about how work impacts waiver eligibility, Social Security Insurance, and other income-based benefits.

The DARS Referral Process is Daunting and Time-Sensitive

To access supported employment services through the DD waivers, the support coordinator must assure that supported employment services are not available through the Department of Rehabilitative Services (DARS) (§110 of the Rehabilitation Act of 1973, §110) or, for individuals younger than 22 years of age, the local school system (§§ 602(16) (17) of the Individuals with Disabilities Education Act, §602(16) (17)). The DARS/ Vocational Rehabilitation (VR) referral process is very time consuming. It can be months before an eligible individual is referred to supported employment services through the DD waivers. This process delays people's ability to access needed DD waiver services which, in some cases, can offer more comprehensive services than DARS.

Note on Sheltered Workshops in DBHDS Employment Data

DBHDS identified 37 people working in sheltered workshops, with waiver funding as the funding source, as of the June 2020 Semiannual Employment Report. Waiver funds cannot be used to fund services in sheltered workshops in Virginia, in compliance with the Workforce Innovation and Opportunity Act (WIOA) and the Home and Community Based Services (HCBS) Settings Rule. DBHDS attributes this count to individuals attending a waiver-funded day program that also offers sheltered workshop activities. Even when waiver funds do not directly support sheltered workshops, it raises the question of whether waiver-funded day programs are financially benefiting sheltered workshops.

Recommendations to Expand Supported Employment

Recommendation 1: The General Assembly should direct the Departments of Medical Assistance Services (DMAS), the Department of Behavioral Health and Developmental Services (DBHDS) and the Department of Aging and Rehabilitative Services (DARS) to study options for designing and implementing a value-based purchasing model for supported employment services in Virginia. The study should include an assessment of other states like Wisconsin that use a value-based purchasing model to reward providers for supporting individuals with a spectrum of support needs in sustained job placements.

Recommendation 2: DBHDS should invest in training and resource development to cultivate a pool of supported employment subject matter experts who can provide technical assistance to support coordinators and others navigating the various and complex processes for accessing supported employment services.

Recommendation 3: DBHDS should require support coordinators to educate individuals with disabilities and their families about the basic impact of employment on benefits and the Benefits Planning service prior to the official Individual Support Plan meeting, consistent with the DOJ Settlement Agreement Compliance Indicator #14.

Recommendation 4: The Commonwealth of Virginia should develop and implement a plan to phase out sheltered employment settings and the use of Section 14(c) certificates of the Fair Labor Standards Act (FLSA). Resources should be shifted to support competitive integrated employment and individuals currently served in sheltered employment settings should be transitioned into competitive integrated employment. This is similar to a recommendation in the VBPD's 2017 Employment Assessment.

Recommendation 5: In the next Semiannual Report on Employment Services, DBHDS should clarify the use of Medicaid HCBS funding to fund services in sheltered workshops.

Recommendation 6: The Commonwealth must ensure employment is accessible to all people on the DD waivers, including those with higher support needs. DBHDS and DARS should explore ways to invigorate customized employment in Virginia, including adding customized employment as a unique and unduplicated service in the DD waivers that would provide more hours for job exploration, job tailoring, coaching, and extended assistance to employers.

Recommendation 7: DBHDS should add to their data tracking the number of individuals in waiver employment by SIS level to support the development of employment strategies for all. DBHDS should provide a summary of this data in their Semi-Annual Report on Employment Services.

Opportunities to Supported Integrated Day Services

Integrated day options are not feasible for many people with disabilities. Key barriers that were identified include a lack of awareness about the service options, a failure to address individual

barriers to community activities, and a lack of providers for these new services. This section explores these key barriers.

Community Engagement Goals Are Not Fully Explored nor Pursued

People must receive proper education and supports in order to access the Community Engagement service. Under the Settlement Agreement, support coordinators are expected to have discussions around community engagement that include: “determining the individual’s interest; identifying and addressing barriers to community engagement; setting community engagement goals and planning to further educate individuals who are not currently interested in CE about its benefits.” However, these expectations have not been met.

Many individuals are not adequately informed about community engagement during service planning. In a review of 99 ISPs, the Expert Consultant of the Independent Reviewer found that 58 percent of the individuals expressed having no interest in Community Engagement. Yet, only four percent (two people) of those people have a plan to further educate them about Community Engagement (Fletcher D. , 2020). The Expert Consultant noted that, based on record review, some support coordinators (SC) did not understand what Community Engagement was, with many reporting that participation in a Group Day program was Community Engagement. This lack of education likely contributes to the limited interest in community engagement.

When people do express an interest in community engagement but encounter barriers, those barriers are often not addressed. The Independent Reviewer found that barriers to Community Engagement were only addressed for 34 percent of the sample of Individual Service Plans that he reviewed. This data underscores that individuals need more support in addressing barriers to community engagement through person-centered planning. In addition, data shows that community involvement goals were set for only 38 percent of the individuals who had ISP meetings, which is far lower than the Commonwealth’s target of 86 percent (Fletcher D., 2020).

Providers Report Some Barriers That Limit Development of New Day Services

As discussed earlier in the report, utilization of the new day services has grown, but still lags far behind utilization of less integrated day service called Group Day. VBPD interviews in March and April of 2021 with providers and advocates identified two key barriers to further developing the integrated day services. These barriers include documentation requirements and inadequate reimbursement rates.

Providers report being limited by onerous documentation requirements when providing multiple day services. Providers are interested in providing multiple day services to expand service options, grow provider capacity, and meet individualized needs. For example, a mix of Community Engagement, Group Day and Community Coaching services may be appropriate to provide to the same individual. However, the ISP and documentation requirements are often redundant and time intensive. Providers report that the paperwork required for each service discourages them from providing a mix of services to the individual.

Providers also report that the reimbursement rate does not support a safe ratio of staff. The 1:3 staff to service recipient ratio, and the reimbursement rate for community engagement, do not take into account the need to have two staff to ensure safety and individualized supports. For safety and best practice, many providers require at least two staff members to accompany individuals in the community. As the rate does not often support a 2:3 staffing ratio, providers do not feel they can offer the service safely or to individuals who may need 1:1 support to participate in community activities.

Recommendations to Support Integrated Day Services

Recommendation 8: The Department of Medical Assistance Services (DMAS) and the Department of Behavioral Health and Developmental Services (DBHDS) should develop provider capacity benchmark goals based on service need estimates regionally for Workplace Assistance, Community Guide and Community Coaching and develop incentive options and other strategies to increase provider capacity to meet the benchmark goals.

Recommendation 9: DMAS and DBHDS should explore options to streamline and eliminate redundancy in the Plan for Supports across day services when one provider is providing multiple services including Community Engagement, Group Day, and Community Coaching services.

Recommendation 10: DMAS and DBHDS should ensure the reimbursement rate for the provision of Community Engagement accurately reflects service delivery design and cost including a service delivery model of two staff and three individuals in the community.

Opportunities to Empower Individuals

In addition to addressing issues with service design and reimbursement, it is important that people with disabilities are empowered to make informed choices about their services and that their choices are honored. Based on feedback from self-advocates, family members, and stakeholders, an individual's ability to benefit from integrated employment and day services depends on strong advocacy skills (by the individual and/or their natural support network) and person-centered planning that is responsive to an individual's preferences. Please see the discussion of these issues earlier in this report, on pages 21 through 24 of the Residential Services Assessment, all of which is relevant to Day and Employment Services.

Recommendations to Support Individual Empowerment

Recommendation A: The Department of Behavioral Health and Developmental Services (DBHDS) should incentivize Community Service Boards, possibly through a pilot project, to incorporate self-advocates in paid positions to bring perspective and experience to the training of support coordinators, including adding a self-advocate-led module in the required support coordinator training modules. The self-advocates can provide guidance through lived experience on the education of individuals and families about services and supports, and principles of person-centered planning and individualized supports. *(Recommendation also included in the residential services assessment)*

Recommendation B: The Department of Medical Assistance Services (DMAS) should consider establishing and seeking General Assembly approval of person-centered facilitation as a distinct, non-duplicative waiver service that would provide more support and expertise to tailor service options to an individual's needs and goals like in Kentucky, where "person-centered coaching" services provide "for modeling, monitoring, assessing and implementing the person-centered plan." *(Recommendation also included in the residential services assessment).*

Recommendation C: DMAS and DBHDS should broaden the qualification requirements for Peer Mentors to include competitive integrated employment and/or demonstrated leadership abilities and leadership roles in organizations and in their communities. A peer mentor could be a person who chooses to live with their family, is competitively employed and actively involved in the community with a robust social life.

APPENDIX A: Focus Groups

The experience of individuals using waiver services is the most important indicator of service quality and success. To find out more about the personal experience of individuals using Day and Employment waiver services, VBPD worked with the Arc of Virginia to host peer-led focus groups of adult individuals using waiver services. In seven sessions in March 2021, a total of 34 individuals gave feedback on their experience and preference regarding Residential services and where they live and how they used Day and Employment services and supports.

Characteristics of Participants Interviewed

- Twenty-three of the 34 interviewed individuals lived in their own home or in a supported-living apartment. Of those 23, 17 lived by themselves, and six lived with one other person.
- Among the other participants, seven lived in family members' homes. Three lived in group homes, and one lived with another family in a sponsored residential home.
- Twenty participants were employed in the community currently or immediately prior to the pandemic. One had retired from competitive integrated employment. Thirteen were not employed.
- Eight of the 13 unemployed participants expressed interest in employment opportunities.

Overall, participants were more likely to live independently and be employed than the total DD waiver population. Some participants discussed successes in living on their own and working in competitive, integrated employment. Others talked about challenges and barriers they faced in living more independently or finding and maintaining a job. Below is a list of key themes related to day services and employment that emerged.

Key Themes from Focus Group Discussions

Living Independently

- **Importance of family support in accessing independent housing:** Family support played a key role in helping individuals move into their own homes or Supported Living apartments. Seventeen of the 23 people living independently said they had family support. Only four people living independently said they did not have family support. Participants said that their family helped them find apartments, told them about independent living options and helped them learn independent living skills like cooking, cleaning, and budgeting. Individuals who had no family support said that they navigated the system on their own and with the help of support coordinators.
- **Role of rental subsidies.** The majority of participants who lived in their own home said that they received financial support to help them pay their rent. Some of the participants were able to identify the specific form of rental assistance, such as

Housing Choice vouchers and the State Rental Assistance Program (SRAP), while others were unsure.

- **Need for financial literacy training and support.** Several participants who lived independently said they need to learn budgeting skills as part of living on their own. Making a budget and figuring out how much money they had every month was a new and important task for people who had previously lived with their family or in a group home.
- **Concerns about level of support.** One of the most common barriers people cited to living independently was concern about receiving adequate supports. Several participants were concerned that they would not be able to get 24 hour/seven day a week support in their own homes. Additionally, three participants who currently lived independently or in Supported Living apartments said that they had issues getting one-on-one supports and finding Personal Care Assistants (PCAs) to consistently assist them.
- **Innovative Uses of Assistive Technology (AT) and Environmental Home Based Supports (EHBS):** AT and/or EHBS helped many of the participants maintain and increase their independence. Interesting examples included:
 - Biometric or keypad locks to reduce the need to remember and handle physical keys
 - Vibrating alarm clocks to wake up
 - Stovetop guards to turn off stove automatically
 - Security camera and alarm systems shared with parents over the internet
 - “Smart assistants” like Alexa® to remember appointments, help with cooking and set medication reminders
 - A smoke alarm programed with the voice of a participant’s mom providing instructions on what to do if the alarm goes off
 - Several participants said AT and/or EHBS would make living independently easier, including access to technology like camera doorbells and other “smart home” technologies that reduce the need to move around the home or apartment. Despite the importance of AT/EHBS, several people said they had difficulty getting the AT/EHBS they needed through the waiver, and that it required too much time and paperwork.
- **Being listened to and heard:** When asked what advice they would give to others interested in living on their own, several advocates emphasized the importance of speaking up about what they want and where they want to live. Others felt that their family and/or support coordinators discounted their desire to move out of their family home into a more independent setting.
- **Peer Mentor Supports:** Several participants said they were eager to participate in the new Peer Mentor service offered through the DD waivers. Participants saw this

as a way to help other individuals prepare to live on their own. As peer mentors, they would be paid for their expertise.

Employment

- **Importance of a responsive job coach:** Focus group participants talked about the importance of a job coach in helping them find a job that matched their interests and skills. One participant's job coach matched him with his "dream job," using his interest in athletics to connect him with a job at a university athletic center. Another participant found a successful match for her interests and skills on her third job placement. Yet, several participants had disappointing experiences with job coaches. One participant who needs personal assistance was told by her job coach that she would need to "work on [her] independent living skills," before she could get a job. The Job Coach ultimately did not help her with a placement and the individual never got a job.
- **High satisfaction with employment:** All the individuals interviewed who were employed said they enjoyed working. Several respondents had jobs with the same company for many years. Others had to try several jobs before they found one that was a match for their interests and skills.
- **Concern about impact on benefits:** Benefits were cited as a common barrier, both for participants who would like a job and those who were already employed but would like more hours. Participants voiced concern that they would lose access to their DD waiver, Supplemental Security Income, or other benefits if they earned too much income.
- **Concern about personal assistance support:** Three out of the 8 participants (37 percent) who would like a job expressed concern about their ability to get personal assistance services while at work. These participants were interested in working but feared they would not have a personal assistant who could help them use the restroom or eat and drink. Without this key service, participants are unable to spend significant time in a workplace.

APPENDIX B: Family Member Survey

VBPD used an online survey to gather information from family members of adults on the DD waivers. Requests to participate were distributed through Facebook, VBPD Constant Contact email and through other stakeholder and advocacy organizations. In total, 91 people responded. 49 people had an adult family member using services available through the DD waivers. For the purposes of analysis, only those 49 respondents are included in the data. The survey used skip logic, so respondents only answered questions that were relevant to their situation.

Characteristics of Participants

- **DEMOGRAPHICS:** Eighty-six percent of respondents identified as parents, 41 percent as guardians, 14 percent as someone who assists with supported decision making and five percent as a sibling. The average age of the family member using waiver services was 29. 39 respondents provided racial data for their family member. 83 percent of respondents identified their family member as White, 13 percent as Black or African American, and 2.5 percent identified as Asian or Asian American.
- **WAIVERS:** Forty-one percent had a family member on the CL waiver, 41 percent on the FIS Waiver, two percent on the BI waiver and seven percent unknown waiver.

Access to Information

Out of 44 respondents, 57 percent agreed with the statement *“I have had a positive experience getting the information I need about available DD waiver services.”* Eleven percent were neutral, and 32 percent disagreed. Respondents cited *“Advocacy/ Family Support Organization”* as the most commonly used resource to get information about available DD services. CSB Support Coordinator, Friends, and the Internet were other top choices.

Independent Living

Four out of five respondents said that *“Having an available provider organization skilled at supporting people in their own home”* significantly contributed to their family member living in their own home or apartment.

Fifteen of 37 (41 percent) respondents said their family member was *“interested in living in a more independent living situation (e.g., their own home/apartment with or without a roommate) with the supports they need.”* 13 (35 percent) answered *“I don’t know.”*

Barriers to Independent Living

Twelve respondents ranked factors that *“contributed to your family member’s inability to access a more independent housing option.”* The top five factors that ranked either *“significantly”* or *“moderately”* were:

- Health and safety concerns (75 percent)
- Cannot locate affordable housing (e.g., cost of housing/housing subsidy not available) (50 percent)
- It's hard to plan for the supports my family member needs if living in independent housing (50 percent)
- Providers not in my area (41 percent)
- No access to public transportation (41 percent)

Of nine respondents who said that their family member was not interested in living independently, eight respondents identified factors that contributed to the decision. The top four factors that ranked either “significantly” or “moderately” were:

- My family member likes where they live and doesn't want to change (86 percent)
- Health and safety concerns (86 percent)
- My family member has support needs that cannot be met in a more independent housing option (75 percent)
- I don't trust the system to provide needed supports (71 percent)

Residential Services: Themes from Family Survey

In reviewing the open ended responses from family members, the following themes emerged. Quotations from survey responses show the different ways each of these issues affects individuals and families.

- Many families confront a lack of options for more independent living arrangements:
 - Family members expressed a need for more choices and options for independent living. Places families visited were not safe and not what they wanted for their child and that they would not expect their child to live somewhere they would not live. “There needs to be more choices allowed in living. The places we have been told about are not what we want for our child. I will not expect her to live somewhere I would not live.”
 - Family members shared challenges with locating personal attendant services and the difficulty in maintaining those services due to the hourly wage. One family member shared that finding an apartment complex that is safe and has staff onsite to assist as needed does not exist in their county. “Personal attendant services support my son to live in his own apartment, but it is often hard to find and maintain workers due to hourly pay. Finding an apartment complex that is safe and has staff on sight available to assist as needed or drop in does not exist in our county.”
- Family members struggle to find independent residential services for individuals with significant behavioral or medical needs:
 - “There are very few service providers in the area who are able to support him due to extreme behaviors and medical issues. Unfortunately we have not been able to find a suitable option for him.”

- “[Our daughter] would like to try living in an apartment but would need staffing 24-7. We do not even know where to begin with this and the thought that we will need to find a caretaker, train them and then they will likely leave because the pay stinks and then we start over again is daunting.”
- Family members often provide supports that cannot be currently duplicated in paid waiver services:
 - “The waiver does not provide supports that are needed to live as independently as my son has thus far. I have to do monthly and annual paperwork re: rent and utility payment, reporting wages to Social Security, reporting income to Social Services, scheduling monthly & annual meetings with housing authority, DD waiver case manager, services facilitator, ISP meetings (which are a joke), SIS meetings, etc. I hire, train, and schedule his staff. I coordinate his and staff’s weekly schedules and activities. My son will not be able to maintain his current situation living in his own apartment when I am gone unless the state somehow provides these services.”

Survey respondents answered how their family members spent most of their time (Figure 15)

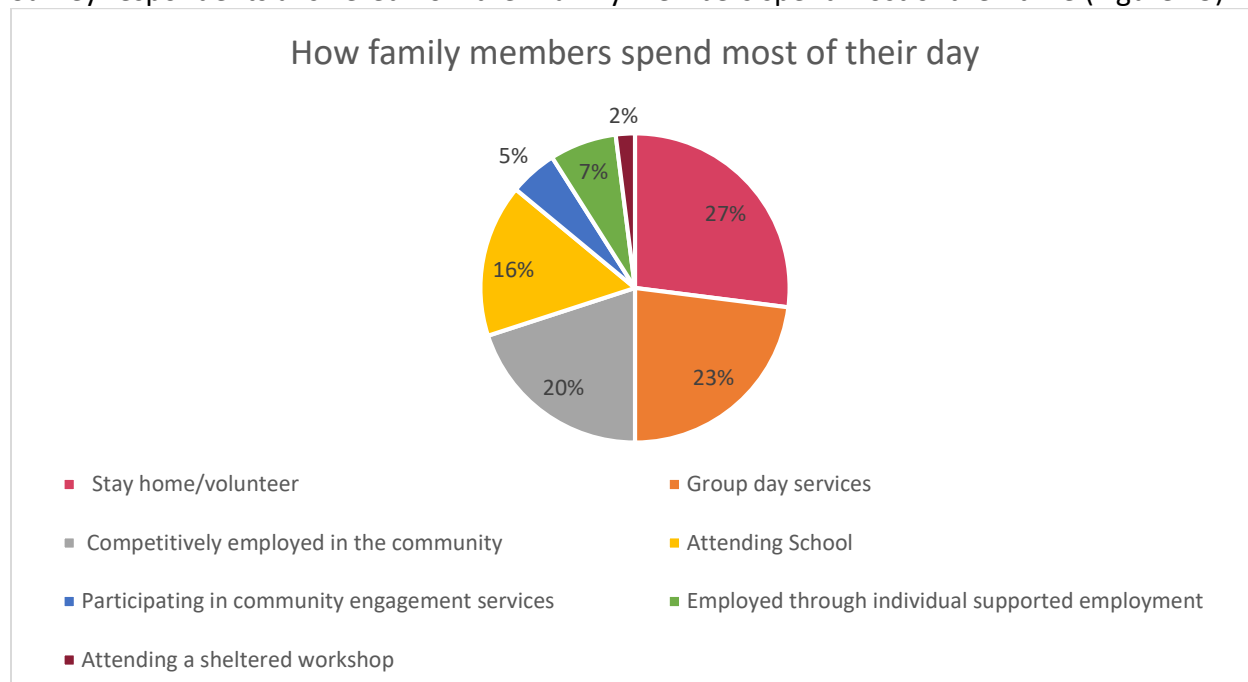


Figure 15: Responses from Family Member Survey, March 2021

The four most common activities were:

- Stay home/volunteer (27 percent)
- Group day services (23 percent)
- Competitively employed in the community (20 percent)
- Attending School (16 percent)

Thirty-five percent reported that their family member spent most of their day using day or employment waiver services. Twenty-three percent used the waiver-funded Group Day service. Only 12 percent used the waiver services of Community Engagement and Individual Supported Employment. No one used group Supported Employment.

Twelve respondents identified the following supports their family member receives while working:

- Job coaching (90 percent)
- Natural supports/none (36 percent)
- Workplace assistance through the waiver (nine percent)

No one reported that their family receives personal assistance services.

Respondents whose family member was not currently employed were asked if the family member was interested in employment. Of the 32 responses, 53 percent said yes, 31 percent said no and 16 percent did not know. Fourteen respondents identified factors that contribute to their family member's lack of employment. The top four factors ranked either "significantly" or "moderately" were:

- Unable to find a good match based on my family member's interests (57 percent)
- Not enough support while on the job (57 percent)
- Inadequate job training opportunities (50 percent)
- It's hard to plan the supports my family member needs to be successful (50 percent)
- My family member tried employment and was not successful (50 percent)

Employment and Day Services: Themes from Family Survey

In reviewing the responses from family members, the following themes emerged:

- **Lack of individualized job coaching.** Job coaching is often not tailored to the individual's interests and skills. The majority of respondents who had unemployed family members listed "Unable to find a good match based on my family member's interests" as a significant factor in lack of employment. Feedback from respondents included:
 - "Every time a new agency works with my daughter we have to start over with getting to know her and her interests. She worked with DARS for a year and her case was dropped because they could not find her a job. However, they did not seem interested in focusing on her interests instead they used their reliable employers to try various jobs out that we knew would not work."
 - "We have not been successful in being able to explore customized employment and the job coach we used once did not have the needed skills to support my child and was very condescending."
- **Use of waiver-funded employment services was less common.** Of the 12 family members who worked, only 4 used ISE and 1 used Workplace Assistance. However, 90 percent of employed family members had a job coach. Presumably, those individuals

not receiving ISE had a job coach funded through DARS. Notably, some respondents volunteered in open-ended comments that job placement services had been unsuccessful.

- **Family members often did not discuss employment during ISP meetings.** Of 32 respondents, 10 said employment had not been discussed during the annual ISP meeting in the past two years.
- **Some respondents point to lack of skills and support as reasons for unemployment.** 5 out of nine respondents who identified factors for why their family member was not interested in employment listed *“My family member does not have the job training or skills to be employed”* as a factor. Thirteen out of 14 respondents said lack of job training was a factor in their family member’s unemployment. Thirteen out of 14 respondents also identified lack of support on the job as a factor.
- **Family members were more likely to use Group Day services than Community Engagement services.** Although the sample size in the survey was small, it reflected the statewide trend of Group Day being used more often than Community Engagement. Additionally, more family members stay home or volunteer during the day than use Community Engagement.

Appendix C: Stakeholder Discussion Groups

On March 30, 2021, stakeholders discussed barriers to using and/or offering the most integrated service options and recommendations to increase their utilization. The following stakeholders participated:

- Jennifer Fidura, Virginia Network of Private Providers
- Debra Fults, Center for Independent Living
- Maureen Hollowell, Center for Independent Living
- Tonya Milling, Lucy Cantrell, the Arc of Virginia
- Karen Tefelski, VaACCSES
- Jennifer Faison, Virginia Association of Community Services Boards

Residential Assessment Works Cited

- Barth, S., Lewis, S., & Simmons, T. (2020). *Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences; Report to the Medicaid and CHIP Payment And Access Commission*. Retrieved from <https://www.macpac.gov/wp-content/uploads/2021/01/Medicaid-Services-for-People-with-Intellectual-or-Developmental-Disabilities- percent E2 percent 80 percent 93- Evolution-of-Addressing-Service-Needs-and-Preferences.pdf>
- Dinora, P., & Prohn, S. (2020). *Virginia Cost and Outcomes Project: An Analysis of the Relationships between Support Needs, Service Use, and Personal Outcomes for People who Use Developmental Disability Waiver Services In Virginia*. Partnership for People with Disabilities; Virginia Commonwealth University.
- Fletcher, D. (2020, December 15). Report of the Independent Reviewer, *United States v. Commonwealth of Virginia*. E.D. Va., No. 3:12 CV 059. Retrieved from <https://dbhds.virginia.gov/assets/doc/settlement/indreview/201215-17th-report-to-the-court-312-cv-059-public.pdf>
- Friedman, C. (2017). Community integration of people with intellectual and developmental disabilities: A national longitudinal analysis. *Disability and Health Journal*, 10(4), 616-620. Retrieved from <https://www.c-q-l.org/wp-content/uploads/2020/02/CQL-2017-Friedman-Trends-in-HCBS-waiver-utilization-for-people-with-IDD.pdf>
- Giodorno, S., & Bradley, V. (2018). *What Do NCI Data Tell Us About the Characteristics and Outcomes of Young Adults Receiving Services?* National Core Indicators; NASDDDS and HRI. Retrieved from <https://www.nationalcoreindicators.org/resources/data-briefs/>
- Herman Soper, M. C., & al., e. (2018). *Achieving Value in Medicaid Home- and Community-Based Care: Considerations for Managed Long-Term Services and Supports Programs*. Retrieved from https://www.chcs.org/media/Achieving-Value-in-Medicaid-Home-and-Community-Based-Care_091818.pdf
- Houseworth, J. R. (2018). *Developments in living arrangements and choice for persons with intellectual and developmental disabilities*, Policy Research Brief, 27(1),. University of Minnesota, Institute on Community Integration. Retrieved from <https://ici.umn.edu/products/972>
- Joint Filing of Complete Set of Agreed Compliance Indictators, *United States v. Commonwealth of Virginia*. E.D. Va., 3:12CV59-JAG (E.D.Va, January 14, 2020).
- Kardell, Y. B. (2020). *Person-Centered Planning Facilitation Summary of Research and Findings*. Cambridge, MA: National Center on Advancing Person-Centered Practices and Systems. Retrieved from https://ncapps.acl.gov/docs/NCAPPS_IDAHO_PCPFacilitationSummary_200707.pdf
- Larson, S., Taylor, B., Pettingell, S., Sowers, M., & Bourne, M. (2020). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2017*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from <https://ici.umn.edu/products/zFtYlbssQTst8M56OkOApQ>
- Lawrence, J. (2020). *Person-Centered Thinking, Planning, and Practice: Representative Examples of State Definitions*. Cambridge, MA: National Center on Advancing Person-Centered

- Practices and Systems. Retrieved from https://ncapps.acl.gov/docs/NCAPPS_Definitions_RepresentativeExamples_200930.pdf
- Mills, L. (2018, November 30). *Value-Based Purchasing: Opportunities in Medicaid Managed Home and Community-Based Services*. Retrieved from New York Alliance for Inclusion and Innovation : https://nyalliance.starchapter.com/images/downloads/lmillsvbp_in_mltss_for_ppl_with_idd_lmills_ny_11_30_18.pdf
- National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute. (2020, November 17). *National Core Indicators. Chart Generator 2017-18*. Retrieved from <http://www.nationalcoreindicators.org/charts/>
- National Council on Disabilities. (2015). *Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community*. Retrieved from <https://ncd.gov/publications/2015/02242015>
- Settlement Agreement, *United States v. Commonwealth of Virginia*. No. 3:12 CV 059 (E.D. Va., August 23, 2012). Retrieved from <https://dbhds.virginia.gov/doj-settlement-agreement>
- Tanis, E. S. (2020). *The State of the States in Intellectual and Developmental Disabilities*. Aurora: University of Colorado Anschutz Medical Campus.
- The State of Connecticut Departmental of Developmental Services Self Advocate Coordinators. (2007). *A Guidebook on Self Advocacy*. State of Connecticut Departmental of Developmental Services. Retrieved from https://portal.ct.gov/-/media/dds/selfadvocate/a_guidebook_on_self_advocacy100107.pdf
- Virginia Department of Behavioral Health & Developmental Services. (n.d.). *Shared Living Toolkit*. Retrieved from <https://dbhds.virginia.gov/assets/doc/DS/pd/final-shared-living-toolkit.pdf>
- Virginia Department of Behavioral Health & Developmental Services. (2019). *Virginia Quality Service Reviews: Year 4 Annual Report July 2018 – June 2019 (FY19)*. Retrieved from <https://www.dbhds.virginia.gov/assets/doc/QMD/cqm/dbhds-qsr-year-4-annual-report.pdf>
- Virginia Department of Behavioral Health & Developmental Services. (2019) *Descriptions from Virginia DBHDS Guide, Navigating the Developmental Disability Waivers: A Guide for Individuals, Families, and Support Partners*. Retrieved from <http://drive.google.com/file/d/1cYSDNb58t-kK4CrhBcl3xa4tQUWn6rzU/view>
- Virginia Department of Behavioral Health & Developmental Services. (2020). *Independent Housing Outcomes Table, September 2020*. Retrieved from https://dbhds.virginia.gov/assets/doc/DS/housing/Housing_Outcomes/dds_housing-outcomes-table_w_comptimeline_09_30_2020.pdf
- Virginia Department of Behavioral Health & Developmental Services. (2021). *Virginia's Plan to Increase Independent Living Options: Action Plan Update January 29, 2021*. Retrieved from https://dbhds.virginia.gov/assets/doc/DS/housing/vpiilo_cy2021_final.pdf
- Virginia Department of Behavioral Health & Developmental Services. (2020). *Residential Settings Trend Report FY 2021, Quarter 1*.
- Virginia Department of Behavioral Health & Developmental Services. (May 2020). *Provider Data Summary: State of the State*. Retrieved from <https://dbhds.virginia.gov/developmental-services/provider-development>

Virginia Department of Behavioral Health & Developmental Services. (November 2020).

Provider Data Summary: State of the State, November 2020. Retrieved from

<https://dbhds.virginia.gov/developmental-services/provider-development>

Virginia Department of Medical Assistance Services and The Department of Behavioral Health and Developmental Services. (2015). *My Life, My Community: Medicaid Intellectual and Developmental Disability Waiver Redesign; Report to the Governor and General Assembly*. Richmond, VA. Retrieved from

<https://rga.lis.virginia.gov/Published/2015/RD385/PDF>

Supported Employment and New Day Services Assessment Works Cited

- Barth, S., Lewis, S., & Simmons, T. (2020). *Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences; Report to the Medicaid and CHIP Payment And Access Commission*. Retrieved from <https://www.macpac.gov/wp-content/uploads/2021/01/Medicaid-Services-for-People-with-Intellectual-or-Developmental-Disabilities- percent E2 percent 80 percent 93- Evolution-of-Addressing-Service-Needs-and-Preferences.pdf>
- Fletcher, D. (2019, June 13). Report of the Independent Reviewer on Compliance with the Settlement Agreement. *United States v. Commonwealth of Virginia*. E.D. Va., Civil Action No. 3:12 CV 059. Retrieved from <https://dbhds.virginia.gov/doj-settlement-agreement>
- Fletcher, D. (2020, December 15). Report of the Independent Reviewer, *United States v. Commonwealth of Virginia*. E.D. Va., No. 3:12 CV 059. Retrieved from <https://dbhds.virginia.gov/doj-settlement-agreement>
- Joint Filing of Complete Set of Agreed Compliance Indicators, *United States v. Commonwealth of Virginia*. E.D. Va., 3:12CV59-JAG (E.D.Va January 14, 2020). Retrieved from <https://dbhds.virginia.gov/doj-settlement-agreement>
- Herman Soper, M. C., & al., e. (2018). *Achieving Value in Medicaid Home- and Community-Based Care: Considerations for Managed Long-Term Services and Supports Programs*. Retrieved from <https://www.chcs.org/>
- Kardell, Y. B. (2020). *Person-Centered Planning Facilitation Summary of Research and Findings*. Cambridge, MA: National Center on Advancing Person-Centered Practices and Systems.
- Mills, L. (2018, November 30). *Value-Based Purchasing: Opportunities in Medicaid Managed Home and Community-Based Services*. Retrieved from New York Alliance for Inclusion and Innovation : https://nyalliance.starchapter.com/images/downloads/lmillsvbp_in_mltss_for_ppl_with_idd lmills ny 11 30 18.pdf
- National Association of Medicaid Directors. (2017, January). *Medicaid Value-based Purchasing: What Is It & Why Does It Matter?* Retrieved from NAMD: https://medicaiddirectors.org/wp-content/uploads/2017/01/Snapshot-2-VBP-101_FINAL.pdf
- National Core Indicators. (December 2011). *NCI Data Brief:What Work Means: What does NCI tell us about the quality of life of adults with intellectual and developmental disabilities who are employed in the community?, Issue 5*. Retrieved from <https://www.nationalcoreindicators.org/resources/data-briefs/>
- National Council on Disability (NCD). (2020). *2020 Progress Report on National Disability Policy: Increasing Disability Employment*. Washington, DC: National Council on Disability (NCD). Retrieved from <https://ncd.gov/progressreport/2020/2020-progress-report>
- Settlement Agreement, *United States v. Virginia*, Civil Action No. 3:12 CV 059 (United States District Court, Eastern District of Virginia August 23, 2012). Retrieved from <https://dbhds.virginia.gov/doj-settlement-agreement>

- The State of Connecticut Departmental of Developmental Services Self Advocate Coordinators. (2007). *A Guidebook on Self Advocacy*. State of Connecticut Departmental of Developmental Services. Retrieved from https://portal.ct.gov/-/media/dds/selfadvocate/a_guidebook_on_self_advocacy100107.pdf
- Virginia DBHDS. (2019). *Virginia Quality Service Reviews: Year 4 Annual Report July 2018 – June 2019 (FY19)*. Retrieved from <https://www.dbhds.virginia.gov/assets/doc/QMD/cqm/dbhds-qsr-year-4-annual-report.pdf>
- Virginia Department of Behavioral Health & Developmental Services. (May 2020). *Provider Data Summary: State of the State*. . Retrieved from <https://dbhds.virginia.gov/developmental-services/provider-development>
- Virginia Department of Behavioral Health & Developmental Services. (November 2020). *Provider Data Summary: State of the State, November 2020*. . Retrieved from <https://dbhds.virginia.gov/developmental-services/provider-development>
- Virginia Department of Medical Assistance Services and The Department of Behavioral Health and Developmental Services. (2015). *My Life, My Community: Medicaid Intellectual and Developmental Disability Waiver Redesign; Report to the Governor and General Assembly*. Richmond, VA. Retrieved from <https://rga.lis.virginia.gov/Published/2015/RD385/PDF>
- Waddell, G. &. (2006). *Is Work good for your health and well-being?* London: TSO. Retrieved from <https://cardinal-management.co.uk/wp-content/uploads/2016/04/Burton-Waddell-is-work-good-for-you.pdf>