



Assessment of Virginia's Disability Services System:

Medicaid Consumer-Directed Services

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2023 Assessment of Medicaid Consumer-Directed Services

First edition

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

The Board selected Medicaid Consumer-Directed Services as a topic area to be assessed. Due to staff vacancies, Board staff were unable to complete and release this assessment in July 2022 as planned. In this Assessment, the Board seeks to determine the benefits and challenges of consumer-directed services. The Board makes recommendations to reduce barriers and challenges and increase individual empowerment in the DD services system.

We appreciate the assistance of the state agencies and other stakeholders that provided information and clarification on the consumer-directed services and oversight responsibilities. The policy recommendations were developed by an ad hoc committee of the Board and approved by the full Board at its June 7, 2023 meeting.

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Statement of Values

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

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

The Virginia Board for People with Disabilities serves as Virginia's Developmental 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 assessment of consumer-directed services for individuals with intellectual disabilities is 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.

Executive Summary

The consumer-directed model of services in Virginia offers an individual more control over their own personal care, companion, and respite services. The ability to self-direct services through this type of model has been shown to increase positive outcomes for individuals. Virginia shares in the nationwide trend of significant growth in consumer-directed (CD) services in the last decade.

PURPOSE OF THE ASSESSMENT

To evaluate benefits and barriers experienced by individuals and families using consumer-directed services.

While the benefits of CD services are many, participants surveyed in preparation for this assessment reported a number of barriers or challenges presented by the current system. This assessment addresses some of the more common challenges CD services participants raised. Virginia has the opportunity to update some of its CD services to provide even more positive outcomes for participants.

The majority of data used for this assessment was provided by the Department of Medical Assistance Services (DMAS) and CD services participants who responded to a VBPD survey to identify the benefits and challenges of CD services. Most of the recommendations are focused on actions required by DMAS. This is unavoidable as DMAS is responsible for administering the CD services available in Virginia's Medicaid programs.

This assessment evaluates the benefits and challenges surrounding consumer-directed (CD) services in Virginia. It is grounded in one overarching key finding: **Medicaid consumer-directed services offer people with disabilities greater control over their services and supports.** The ability to have that control results in increased satisfaction and fulfillment in all aspects of life.

In survey responses, CD services users shared the benefits and challenges they experience. Those challenges are addressed throughout this assessment in the five different categories below. The key findings in each area informed the development of recommendations aimed at improving CD services in Virginia.

Administrative and service authorization processes

Accessing CD services in Virginia can be challenging due to complicated paperwork and administrative procedures. Onboarding new employees, specifically attendants, is confusing and time-consuming, leading to delays in payments and even the loss of attendants. The complex network of entities involved in CD services in Virginia, further exacerbates the difficulties. Each managed care organization (MCO) and fiscal/employer agent (F/EA) entity has its own unique enrollment requirements and paperwork materials, making it even more challenging for services facilitation providers to navigate the system. Streamlining and increasing consistency in paperwork and attendant enrollment processes across fee-for-service

and managed care offerings are central to reducing the administrative burden on all stakeholders, including participants, families, and attendants.

Customer service and satisfaction

Stakeholders in CD services report frequently expressing their concerns and challenges, but their issues often go unaddressed. CD services users face frustration when attempting to resolve problems. Issues include difficulty contacting F/EA staff, inconsistent guidance, a lack of knowledge among F/EA staff, and poor customer service. There is a perceived lack of accountability in the system, and users feel there is no clear process to report issues or provide feedback. Grievance procedures are not readily available, exacerbating the problem.

Furthermore, access to the results of annual MCO satisfaction assessments of customer satisfaction with F/EA services is lacking. The satisfaction levels of CD services participants with services facilitators vary, with some experiencing positive relationships and others facing challenges such as delayed responses, lack of follow-through, turnover, and paperwork errors. The quality of services facilitators significantly impacts the success of utilizing CD services.

Roles and responsibilities & services facilitation

Users of CD services often struggle to understand the roles of different provider entities involved, leading to confusion about whom to contact for assistance. Communication between these entities is lacking, and multiple visits from different providers can feel redundant and time-consuming. Requirements for services facilitation need to be clarified, as many users find monthly meetings burdensome and unhelpful. There is a need for more robust standards to ensure services facilitators are knowledgeable and able to provide valuable support. Services facilitators can play a crucial role in supporting employers of record (EORs) in finding qualified attendants, but survey results indicate limited support in recruiting and hiring. Enhancing the support provided by services facilitators can improve the overall experience of CD services users.

CD services attendants

The healthcare system is facing a workforce crisis, particularly impacting direct support professionals who assist individuals with disabilities. This crisis is further complicated for individuals with limited family and social connections. The demand for personal attendants has increased as more people enroll in consumer-directed services. Low pay, lack of benefits, limited hours, and limited career advancement opportunities contribute to hiring and retention issues. Pay rates for CD services in Virginia are below the national average, and a significant number of home care workers rely on public assistance.

Family members

For some, having a family member serve as the EOR can be a positive experience, but that is not always the case. It is important to consider the unique circumstances and preferences of each person. Flexibility and safeguards are necessary to prioritize the choices and preferences of CD services users. Family members are also an important option to be employed as the

provider of CD services. Allowing legally responsible persons, such as parents of minor children and spouses, during the COVID-19 public health emergency proved to be a tremendous benefit to some families. Addressing the future of these flexibilities post-COVID is a necessary step to ensure users are receiving the services they need.

The recommendations proposed below provide suggestions to address these challenges. Implementing these recommendations would provide users of CD services with better overall customer service, supports, and outcomes.

Recommendations related to administrative and service authorization processes

1. The Department of Medical Assistance Services (DMAS), through a qualified contracted entity, and aligned with the procurement of MCOs and F/EAs contracts, should conduct a CD services attendant enrollment audit to identify all possible enrollment steps and components. Such a process would examine how these requirements vary across entities and help identify baseline requirements. The audit should also assess 1) whether existing requirements are necessary or efficient, 2) whether steps should be taken to reduce the burden of the enrollment process on CD services users, and 3) the complexity of the enrollment process across entities, including the design of the attendant enrollment processes and whether instructions and guidance materials are easily understood. Based on audit findings, DMAS should implement standardized processes across entities.
2. The Department of Medical Assistance Services, in collaboration with the Department of Behavioral Health and Developmental Services and managed care organizations, should create a clear and easily accessible process for participants and their families to understand how authorized hours are determined. This could include providing user-friendly written materials and resources that explain the factors considered when determining authorized hours and information about the appeals process.
3. The Department of Medical Assistance Services should develop a comprehensive data collection system that requires Managed Care Organizations (MCOs) to provide detailed service authorization data. This data should include the number of authorized hours for personal assistance services. By collecting this information, DMAS can better monitor CD services delivery, identify potential issues or areas of concern, and take corrective action as necessary. Additionally, this data could be used to inform future policy and program development, ensuring that CD services meet participants' needs and provide high-quality, person-centered services.

Recommendations related to customer service and satisfaction

4. The Department of Medical Assistance Services should make easily available to the public MCO annual results from the F/EA satisfaction surveys including performance targets, the percentage of respondents completing the survey, and how those

respondents are selected. Additionally, information should be provided regarding the process for remediating areas requiring improvement based on the survey results and performance targets.

5. The Department of Medical Assistance Services should involve stakeholders in discussing and resolving issues related to CD services, such as enrollment, customer service, and services facilitation. It is crucial to engage stakeholders who have a vested interest in CD services to build trust and enhance collaboration. States such as Colorado and Texas have successfully engaged stakeholders through advisory groups, resulting in better processes and services. Inclusive discussions and engagement with stakeholders can lead to improvements in CD services and provide greater outreach and understanding.
6. The Department of Medical Assistance Services should require the MCOs to provide information regarding the grievance/complaint process to all members on an annual basis.

Recommendations related to roles and responsibilities & services facilitation

7. The Department of Medical Assistance Services should create a standardized and user-friendly program guide. This guide should clearly define the roles and responsibilities of each entity involved in CD services, including the EOR, MCO, F/EA, SF, care coordinator, and support coordinator. Additionally, it should document the attendant enrollment criteria as determined by the CD services attendant enrollment audit, as recommended in recommendation number one. By providing a clear and concise guide, users of CD services can better understand the various entities involved and the processes for attendant enrollment, resulting in improved overall service delivery.
8. The Department of Medical Assistance Services and Department of Behavioral Health and Developmental Services should collaboratively develop training and guidance materials (standards of practice) for care coordinators, services facilitators, and support coordinators to facilitate understanding and accountability for roles and responsibilities.
9. The Department of Medical Assistance Services and Department of Behavioral Health and Developmental Services should ensure individuals and families using CD services through a DD waiver are aware that they can choose not to use a services facilitator if another family member or individual's support coordinator can function as the services facilitator. A document outlining the process for choosing not to use services facilitation services should be developed and made available.
10. The Department of Medical Assistance Services should develop and publish jargon-free and easily understood program materials for services facilitators and participants based on the program guide recommended in recommendation number six.
11. The Department of Medical Assistance Services should review the current Services Facilitation training modules to ensure the information provided is up to date. This

review should include updating or removing any out-of-date forms, attachments, or links referenced in the training modules.

12. The Department of Medical Assistance Services (DMAS) should take steps to ensure that individuals who use consumer-directed services receive appropriate care management and support through Cardinal Care. DMAS should work with Managed Care Organizations to develop clear indicators that can help to identify CD services users who may be in need of enhanced care management services, such as individuals who have complex medical needs, are returning home after a hospitalization, or may require additional support to manage their care.

Recommendations related to CD services attendants

13. The General Assembly should take action to improve the compensation for consumer-directed services attendants and to provide a living wage that is consistent with the national average and commensurate with the value of the work performed. Further, the General Assembly should consider implementing regular Cost-of-Living Adjustment (COLA) increases to the personal attendant rate to address the challenges related to low wages, high turnover rates, inflation, and workforce shortages in the home care industry.

Recommendations related to family members

14. The Department of Medical Assistance Services (DMAS) should establish a policy that requires a services facilitator to complete, and review annually, the DMAS 95B form in cases where a family member of an adult who uses CD services requests to become the Employer of Record (EOR). This policy would ensure that the services facilitator reviews the family member's qualifications and suitability for the EOR role and helps to mitigate potential conflicts of interest that may arise in these situations.
15. The Department of Medical Assistance Services (DMAS) should develop clear and comprehensive criteria that allow legally responsible persons to serve as paid attendants under consumer-directed services while ensuring that appropriate safeguards are in place. These criteria should consider the unique needs and circumstances of the individual receiving services, as well as any potential conflicts of interest or concerns related to attendant qualifications or suitability.

Background:

What are Consumer-Directed Services?

Consumer-directed (CD) services allow an individual to hire, train and supervise their own personal attendants for personal assistance, companion, and respite services. This service model offers an individual more control over their services than traditional agency-directed services, in which a provider agency employs an attendant, trains them, and then assigns the attendant to the individual. Virginians in five Medicaid-funded programs have the option to use CD services.

Philosophy of Self-Direction

What Virginia refers to as “consumer-direction” is widely called “self-direction” in research literature and in other state models. Self-direction is an essential part of maximizing autonomy for people with disabilities who depend on quality supports for daily tasks. The philosophy behind self-direction is based on three key principles:

- “(1) People with disabilities are experts on their service needs;
- (2) Choice and control can be introduced into all service delivery environments; and
- (3) Self direction should be available to anyone with a disability, regardless of who is paying for their services.” (Swaine, 464-471).

Self-direction allows the supported individual to decide whom they want to help them and determine how they want to be supported. An individual with a disability can choose to manage their employee, or they can choose a family member or someone else to make such decisions for them. In self-directed services, the Employer of Record (EOR), rather than an agency, trains staff in how to support their needs.

Research shows that self-directed services increase positive outcomes in health, community integration and general wellbeing. Since 2007, studies have shown that CD services is likely to increase overall satisfaction with care and life as a whole (Brown). People who self-direct services are less likely to experience out-of-home placement at an institution or nursing home. Research links self-direction to better medication management, and better oral, dietary and general health outcomes (Bershady, 475-485).

WHO CAN USE CD SERVICES?

Individuals in these Medicaid-funded programs may be eligible for CD Services:

- ✓ Commonwealth Coordinated Care (CCC) Plus Waiver
- ✓ Community Living (CL) Waiver
- ✓ Family and Individual Supports (FIS) Waiver
- ✓ Early and Periodic Screening, and Diagnostic

Self-direction also improves overall family satisfaction with support services. Family members in self-directed programs report lower parenting stress, higher self-efficacy in caring for their child, improvements in overall family functioning and better coping with stressful issues as a family (DeCarlo, 11-21).

Services Eligible for Consumer Direction

Three types of services are eligible for consumer direction in Virginia: personal care, companion services, and respite services. These services are available through Medicaid-funded programs: Developmental Disability (DD) waivers, specifically, the Community Living (CL) and Family and Individual Supports (FIS) waivers; Commonwealth Coordinated Care (CCC) Plus waiver; Early and Periodic Screening, and Diagnostic and Treatment (EPSDT) benefit; and Medicaid Works program. Table 1 describes these services, and indicates through which program the service is eligible with an “X.”

Table 1: Services Eligible for Consumer Direction in a Medicaid-Funded Program, Indicated with an “X”, Source: Department of Medical Assistance Services

Service	Description	DD (CL/ FIS) Waiver	CCC Plus Waiver	EPSDT Benefit	Medicaid Works Program
Personal Care	Personal care services help individuals with their activities of daily living (ADLs) at home, work and other places in their community. ADLs include dressing, bathing, toileting, eating, assistance with self-administered medication and more.	X	X	X	X
Companion Services	Companion services assist adult individuals with housekeeping, shopping and community activities.	X			
Respite Services	Respite services assist the individual with tasks in place of the individual’s family/caregiver, giving the family/caregiver needed time for themselves or other family members. (Consumer-directed services only cover general respite services that do not require a licensed practical nurse or registered nurse.)	X	X		

Roles and Responsibilities in Consumer Direction

Virginia uses the “fiscal/employer agent” model of CD services. In this model, the individual receiving services, or their representative, serves as the “employer of record” (EOR). The EOR has control over their services, as well as responsibility for finding, hiring, retaining, training, directing, supervising, and terminating an attendant that meets the needs of the individual receiving services. A services facilitator (SF) provides support to the EOR in training attendants, completing service authorizations, and conducting annual evaluations. The fiscal/employer agent (FEA) is an agency that provides payroll tasks such as withholding taxes and distributing paychecks.

Data Snapshot: Trends in CD Services

Nationally, consumer-directed services have grown significantly in the last decade. This growth is due in part to increased federal support for consumer-direction. Recognizing the importance of consumer-direction, the Centers for Medicaid and Medicaid Services (CMS) “urged all states...to include self-direction as a component of their overall [Home and Community-Based Services (HCBS)] waiver programs.” (Friedman, 30-39). Between 2011 and 2016, national enrollment in HCBS self-directed programs increased 43 percent to just over 1 million people (Edwards-Orr). As of federal fiscal year 2018, all states, except Alaska, allowed beneficiaries to access Self-directed services through at least one HCBS waiver (Musumeci, 15).

In Virginia, the number of people who use consumer-directed services has increased in recent years, as shown in Table 2. The number of new attendants has decreased in recent years, however. This is a concerning trend because the demand for attendants is expected to grow.

Table 2: CD Services Data Snapshot, Source: Department of Medical Assistance Services

Total Number	FY 17	FY18	FY19	FY20
CD Services Users	19,019	20,337	21,313	26,439
Attendants Through CD Services	25,746	28,044	29,932	30,744
New Attendants	13,306	10,965	10,180	7,838
Attendants That Identified as a Live-in Caregiver	4,167	8,678	10,249	11,466
Services Facilitation Providers	366	405	465	504

Methodology

To evaluate the benefits and challenges of consumer-directed (CD) services in Virginia's Medicaid waivers, the Board analyzed Virginia-specific data and reviewed national research on trends and best practices in HCBS waiver services. Additionally, the Board conducted an electronic survey with individuals and families using CD services to better understand their experiences. This input from people with disabilities and their families was essential in identifying the benefits and barriers of accessing and using CD services. The survey was

disseminated through social media, advocacy organizations, and the Department of Medical Assistance Services. Survey questions and full survey results can be found in Appendix A.

Consumer-directed Services Survey Participants: CD Services User Characteristics

928 people accessed the survey. 802 people completed the questions about services (e.g.: how they/the individual accesses CD services, who answered the survey, who served as employer of record). Characteristics of survey respondents are presented in Table 3.

Table 3: CD Services User Characteristics, Ordered from Greatest to Lowest Percentage, Source: Survey Results

Characteristic	Number of Respondents	Percentage
Medical Program for CD Services	802	100%
CCC Plus Waiver	397	49.5%
Not Sure	152	19.0%
DD Waiver: Family and Individual Supports	136	17.0%
DD Waiver: Community Living	71	8.9%
Medicaid Works	37	4.6%
EPSDT	9	1.1%
Responder Type	802	100%
Employer of Record (EOR) – Other than individual using CD services	557	69.5%
Individual using CD services	122	15.2%
Family member	101	12.6%
Other	15	1.9%
Other natural support	7	0.9%
Employer of Record	802	100%
Family member	586	73.1%
Individual	138	17.2%
Other natural support	38	4.7%
Other	23	2.9%
Not sure	17	2.1%
How Long Using CD services	802	100%
3-5 years	228	28.4%
6-10 years	207	25.8%
More than 10 years	136	17.0%
1-2 years	131	16.3%
Less than 1 year	76	9.5%
Not sure	24	3.0%
Living Situation	764	100%
With family or caregiver	565	74.0%

Independently with roommates	15	2.0%
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Key Findings and Related Recommendations

Benefits of CD Services

Medicaid consumer-directed services offer people with disabilities greater control over their services and supports. Unlike traditional Medicaid programs, where agencies or providers make decisions, consumer-directed (CD) services allow individuals to choose how services are delivered, including when and by whom. This flexibility can provide greater autonomy, choice, and independence, enabling individuals to remain in their homes and communities rather than moving to institutional or other congregate settings.

These benefits are demonstrated in Table 4. Survey participants were asked, “What benefits have you experienced using CD services?” Participants could select more than one response from a list of responses.

Table 4: Reported Benefits, Source: Survey Results

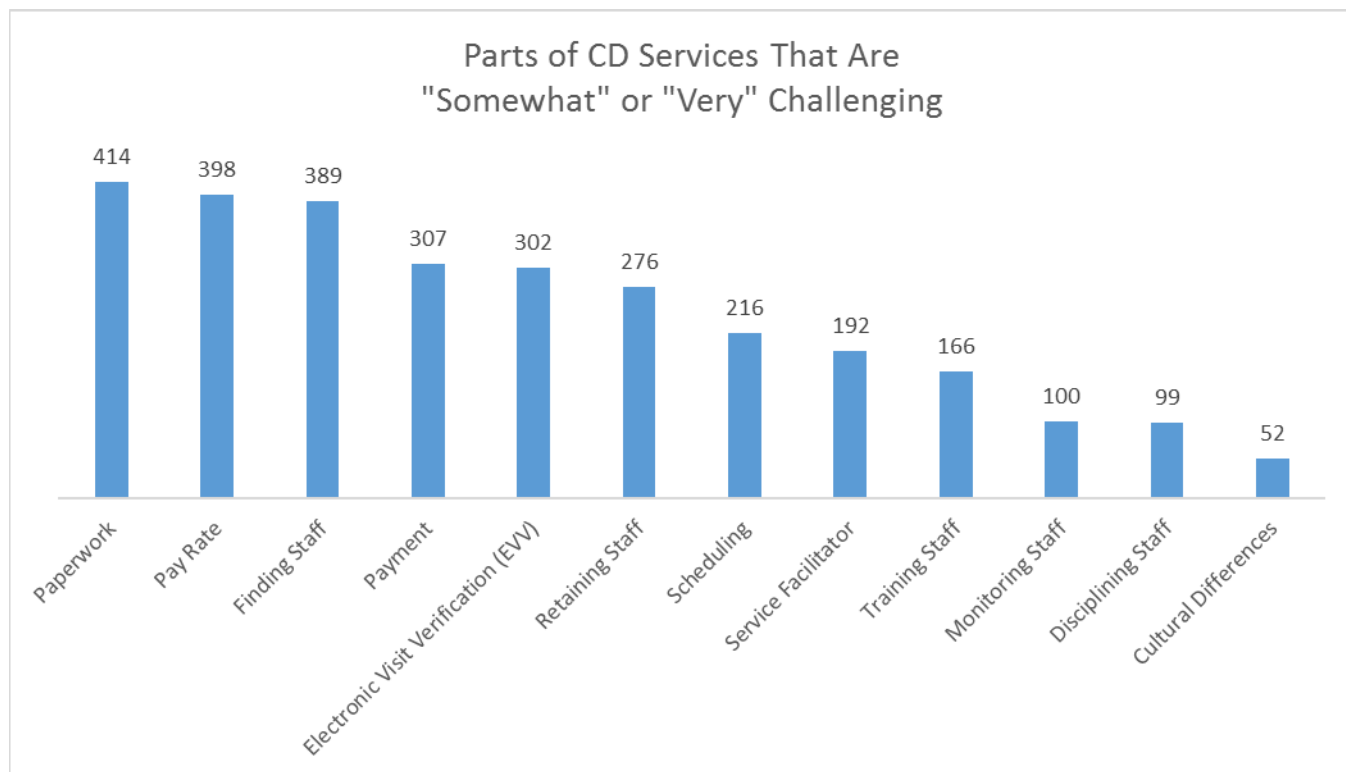
Benefit	Number of Respondents	Percentage
Truly select staff	521	56.1%
Control	454	48.9%
Hire people I know	452	48.7%
Hire family	430	46.3%
Staff hours	418	45.0%
Reliable	345	37.2%
High quality	256	27.6%
Reduced turnover	246	26.5%
Shared interests	211	22.7%
Cultural match	132	14.2%
No benefits	15	1.6%
Not sure	12	1.3%

Challenges of CD Services

Several challenges also came to light through our survey, depicted in Figure 1. Nearly 60% of respondents reported that the paperwork requirements were either somewhat or very challenging. In addition, the vast majority of comments relating to paperwork requirements indicated that the paperwork requirements and processing times hinder hiring staff. Other challenges included pay rates, staff recruitment, and staff retention. On the other hand, cultural differences and disciplining staff were reported as the least challenging. The following sections

discuss these findings and other identified challenges in more detail and provide recommendations to address them.

Figure 1: Reported Challenges, Source: Survey Results



Administrative & Service Authorization Processes

Accessing CD services can be challenging due to complex paperwork and administrative processes. The process of onboarding new employees can be confusing and time-consuming. Employers of Record (EOR) report that the paperwork process to hire an attendant takes too long, attendants do not get paid timely, and there are reports of paperwork getting “lost.” EORs report losing attendants due to these delays. Survey respondents indicated that it is not unusual for onboarding paperwork to take two months or more for correct processing.

Two barriers in the onboarding process reported most often are the volume and complexity of paperwork. A wide network of entities working together to administer CD services in Virginia has created significant difficulty for EORs and other stakeholders. Key entities in Virginia CD services include:

- Virginia Department of Medical Assistance Services (DMAS)
- Six managed care organizations (MCOs)
- Three fiscal/employer agents (F/EA)
- Services facilitation providers

Across this network of entities, each MCO may develop its own distinct attendant enrollment requirements, or hiring process, for CD services. The different F/EA entities affiliated with these MCOs in turn implement different MCO requirements, and each F/EA entity imposes its own unique paperwork requirements and materials for attendants, including varying enrollment packets. Fee-for-services CD services, i.e., when Medicaid pays the provider directly, also have their own distinct enrollment requirements.

In turn, the large network of nearly 500 unique services facilitation providers must become familiar with complex enrollment requirements that are not consistent across the MCO and F/EA arrangements. Services facilitation providers vary in size and, therefore, capacity to adapt to these various enrollment requirements.

Additionally, changes in CD services program offerings (such as providing sick leave for workers who provide CD services) and requirements result in necessary updates to existing enrollment processes. These changes must be implemented across each MCO in collaboration with their F/EA partners. Services facilitation providers must then become familiar with these changing enrollment requirements, which vary somewhat between different MCOs and F/EAs. The potential for confusion is significant.

As one survey respondent succinctly noted, *“Sometimes it is really hard to navigate between 4 big organizations. Medicaid, SF, MCO and Fiscal Agent. If something goes wrong, sometimes no one takes responsibility, and the attendant doesn’t get paid.”*

Simplifying paperwork and attendant enrollment processes require streamlining and greater consistency across fee-for-service and managed care service offerings. Doing so will ease the administrative burden on all other program stakeholders, not only F/EA entities and services facilitators but also participants, families, and attendants.

Recommendation 1: The Department of Medical Assistance Services (DMAS), through a qualified contracted entity, and aligned with the procurement of MCOs and F/EAs contracts, should conduct a CD services attendant enrollment audit to identify all possible enrollment steps and components. Such a process would examine how these requirements vary across entities and help identify baseline requirements. The audit should also assess 1) whether existing requirements are necessary or efficient, 2) whether steps should be taken to reduce the burden of the enrollment process on CD services users, and 3) the complexity of the enrollment process across entities, including the design of the attendant enrollment processes and whether instructions and guidance materials are easily understood. Based on audit findings, DMAS should implement standardized processes across entities.

Additional transparency is needed in the determination of the number of hours an individual is authorized to use, and for a reduction in authorized hours. 43% of survey respondents said the number of authorized hours was not meeting their needs. In addition, CD services users reported that they receive notice that their hours have been reduced when no medical or care

needs have changed. CD services users expressed frustration that their quality of life is negatively impacted when this occurs. Providing more transparency into how an appropriate number of hours is determined by the MCO, DBHDS, or DMAS would give participants a better understanding of the factors that influence authorized hours and allow them to advocate for their needs more effectively. Additionally, greater transparency could help build trust and improve the overall quality of care provided under the CD services program.

Recommendation 2: The Department of Medical Assistance Services, in collaboration with the Department of Behavioral Health and Developmental Services and Managed Care Organizations, should create a clear and easily accessible process for participants and their families to understand how authorized hours are determined. This could include providing user-friendly written materials and resources that explain the factors considered when determining authorized hours and information about the appeals process.

DMAS is unable to provide service authorization data from MCOs. As part of this assessment, the Board requested information regarding service authorization data. DMAS could only provide service authorization data for individuals receiving CD services provided through fee-for-service and could not obtain service authorization data for individuals assigned to an MCO. With MCO service authorization data, DMAS can have a more complete picture to oversee CD services effectively.

Recommendation 3: The Department of Medical Assistance Services should develop a comprehensive data collection system that requires Managed Care Organizations (MCOs) to provide detailed service authorization data. This data should include the number of authorized hours for personal assistance services. By collecting this information, DMAS can better monitor CD services delivery, identify potential issues or areas of concern, and take corrective action as necessary. Additionally, this data could be used to inform future policy and program development, ensuring that CD services meet participants' needs and provide high-quality, person-centered services.

Customer Service and Satisfaction

Despite stakeholders routinely reporting their concerns and challenges with CD services, their issues are frequently left unaddressed. CD services users frequently experience frustration when attempting to resolve issues. In the CD services survey, multiple participants reported problems such as difficulty reaching Fiscal/Employer Agent (F/EA) staff by phone, receiving inconsistent guidance that contradicts previous guidance and a need for improved customer service. In addition, users of CD services report that F/EA staff are often not knowledgeable about processes. Many survey respondents feel that there is insufficient accountability in the current system. Survey comments also indicate that users of CD services feel that there is not an appropriate avenue to report issues, or at the very least, they are unaware of a process. Information regarding grievance procedures is not readily available.

Additionally, people are unable to make informed decisions about which managed care organization (MCO) to choose as their provider because of a lack of transparency surrounding the results of MCO satisfaction assessments. The contracts that MCOs have with DMAS require annual assessments of customer satisfaction with F/EA services, including satisfaction with enrollment, timesheet, electronic visit verification, payroll services, tax processing, call center responsiveness and customer service, and web-based services and information. However, the assessment results and the resulting corrective action plans are not available to the public.

The satisfaction levels of CD services participants with their services facilitator vary. While some participants have a positive experience and a good relationship with their services facilitator, others encounter difficulties such as delayed responses to phone calls, lack of follow-through, high services facilitator turnover, and paperwork errors, which lead to delays in accessing services. The quality of the services facilitator and facilitation services plays a significant role in determining the success of utilizing CD services.

Recommendation 4: The Department of Medical Assistance Services should make easily available to the public MCO annual results from the F/EA satisfaction surveys including performance targets, the percentage of respondents completing the survey, and how those respondents are selected. Additionally, information should be provided regarding the process for remediating areas requiring improvement based on the survey results and performance targets.

Recommendation 5: The Department of Medical Assistance Services should involve stakeholders in discussing and resolving issues related to CD services, such as enrollment, customer service, and services facilitation. It is crucial to engage stakeholders who have a vested interest in CD services to build trust and enhance collaboration. States such as Colorado and Texas have successfully engaged stakeholders through advisory groups, resulting in better processes and services. Inclusive discussions and engagement with stakeholders can lead to improvements in CD services and provide greater outreach and understanding.

Recommendation 6: The Department of Medical Assistance Services should require the MCOs to provide information regarding the grievance/complaint process to all users of CD services on an annual basis.

Roles and Responsibilities & Services Facilitation

Users of CD services often find it challenging to understand the roles of each provider entity, such as support coordinators, care coordinators, and services facilitators (SF). As a result, families may be unsure whom to contact when they have questions or issues. Additionally, there is a lack of communication between provider entities. Moreover, visits from multiple providers can be time-consuming and appear redundant since each provider requests similar information. One survey respondent expresses it this way: *“I feel like there’s an overlap in roles among agencies that are all tasked with, and presented as, managing/coordinating/overseeing services...In reality, it’s not cohesive and becomes confusing. We are left answering the same*

questions and providing the same information to a multitude of people because they are not communicating with each other.”

The requirements of services facilitation need to be clarified. Many CD services users report that services facilitators require monthly meetings with them. For some, monthly meetings are a burden and provide little value. 12 VAC 30-122-150, shown below, states that users of CD services through the Developmental Disability (DD) waivers are not required to receive support from a services facilitator. However, many individuals/families do not know of this flexibility.

12 VAC 30-122-150. Requirements for consumer-directed model of service delivery.

2. Requirements for individual.

...

d. Individuals choosing consumer-directed services may receive support from a CD services facilitator. Services facilitators shall assist the individual or his [Employer of Record (EOR)], as appropriate, in accessing and receiving consumer-directed services. This function shall include providing the individual or EOR, as appropriate, with employer of record management training including a review and explanation of the employee management manual and routine and reassessment visits to monitor the CD services.

e. If an individual choosing consumer-directed services chooses not to receive support from a CD services facilitator, then another family member or caregiver other than the EOR shall perform all of the duties and meet all of the requirements of a CD services facilitator, including documentation requirements identified for services facilitation. However, the family member or caregiver serving as the services facilitator shall not be reimbursed by DMAS for performing these duties or meeting these requirements.

In addition, EORs report that services facilitators often are not knowledgeable about what services are available to the participant and are unable to answer questions. More robust standards are needed to ensure that services facilitators can effectively assist families as needed. Applied Self-Direction, an organization dedicated to creating authentically self-directed, person-centered environments, has developed [Core Standards for Information & Assistance Professionals in Self-Direction](#), which provides useful information for developing appropriate standards to increase the quality of services facilitation services.

Included in the Core Standards for Information & Assistance Professionals in Self-Direction are not only suggestions for minimum qualifications but also philosophical hallmarks of a high-quality professional, necessary skills and core competencies. In addition, the document lays out recommended strategies for training, monitoring and oversight.

One area where services facilitators could have a big impact is more consistently supporting EORs in their search for qualified attendants. CD services survey results showed a strong

relationship between people who reported that their services facilitator ‘helped a lot’ with finding staff and that finding staff was not challenging. Services facilitators should provide skills training and education to assist with the hiring search and onboarding process. Many people using CD services reported limited support with recruiting and finding staff from services facilitators.

Recommendation 7: The Department of Medical Assistance Services should create a standardized and user-friendly program guide. This guide should clearly define the roles and responsibilities of each entity involved in CD services, including the EOR, MCO, F/EA, SF, care coordinator, and support coordinator. Additionally, it should document the attendant enrollment criteria as determined by the CD services attendant enrollment audit, as recommended in recommendation number one. By providing a clear and concise guide, users of CD services can better understand the various entities involved and the processes for attendant enrollment, resulting in improved overall service delivery.

Recommendation 8: The Department of Medical Assistance Services and Department of Behavioral Health and Developmental Services should collaboratively develop training and guidance materials (standards of practice) for care coordinators, services facilitators, and support coordinators to facilitate understanding and accountability for roles and responsibilities.

Recommendation 9: The Department of Medical Assistance Services and Department of Behavioral Health and Developmental Services should ensure individuals and families using CD services through a DD waiver are aware that they can choose not to use a services facilitator if another family member or individual’s support coordinator can function as the services facilitator. A document outlining the process for choosing not to use services facilitation services should be developed and made available.

Recommendation 10: The Department of Medical Assistance Services should develop and publish jargon-free and easily understood program materials for services facilitators and participants based on the program guide recommended in recommendation number six.

Recommendation 11: The Department of Medical Assistance Services should review the current Services Facilitation training modules to ensure the information provided is up to date. This review should include updating or removing any out-of-date forms, attachments, or links referenced in the training modules.

An additional tool that is available to individuals who are enrolled in Virginia’s Medicaid program is DMAS’ Enhanced Care Management through Cardinal Care. The program provides additional care management and support services to individuals enrolled in Virginia’s Medicaid program, including those who use CD services. The program is offered through MCOs and aims to help individuals access appropriate medical care, manage their chronic conditions, and improve overall health outcomes through a responsive member-focused model of care. This

model includes care coordination for Medicaid members with minimal needs as well as three levels of care management based on member needs and intensity: low intensity, moderate intensity, and high intensity. According to a September 2022 presentation by DMAS, care management components include, but are not limited to, the following:

- Supporting the member’s choice to reside in the least restrictive environment;
- Providing comprehensive health risk assessments;
- Developing comprehensive member-centered care plans;
- Providing for interdisciplinary care team collaborations, participation, and communication; and
- Establishing wrap-around community support services, addressing social determinants of health.

Recommendation 12: The Department of Medical Assistance Services should take steps to ensure that individuals who use consumer-directed services receive appropriate care management and support through Cardinal Care. DMAS should work with Managed Care Organizations to develop clear indicators that can help to identify CD services users who may be in need of enhanced care management services, such as individuals who have complex medical needs, are returning home after a hospitalization, or may require additional support to manage their care.

CD Services Attendants

The current workforce crisis is impacting the healthcare system, especially direct support professionals who assist individuals with disabilities to live independently in the community.

For individuals with disabilities who wish to direct their services but have limited family and social connections, this problem is even more complicated. The demand for personal attendants has grown as more people enroll in consumer-directed services. In Virginia, the number of Home Health and Personal Care Aides grew by 58% between 2011 and 2021, with over 55,000 workers counted in 2021 (PHI Workforce Data Center). PHI predicts that demand for Personal Care Aides will increase by 37% between 2018 and 2028, for a projected total of 86,600 job openings by 2028 (PHI, 1).

One of the primary obstacles to CD services reported by EOR survey respondents is the difficulty in finding and retaining qualified attendants. Recruitment and retention has always been a challenge, and it has worsened since the pandemic started. This issue has resulted in people going without the necessary services and supports they require.

Low pay, lack of benefits, limited hours, and few opportunities for career advancement hinder the hiring and retention of employees. These factors exacerbate the workforce shortage.

Virginia’s CD services pay rates lag behind the national average. According to the PHI Workforce Data Center, the median hourly wage for a home care worker in Virginia in 2021 was \$11.06 (PHI Workforce Data Center). In addition, 45% of Virginia home care workers receive

some public assistance (PHI Workforce Data Center). The General Assembly has worked in recent years to address low attendant pay, but there is still work to be done to make personal attending a viable career option. Current pay rates for CD services are \$12.70 per hour statewide and \$16.45 per hour in Northern Virginia. By prioritizing fair compensation for attendants, the General Assembly can help ensure that individuals who rely on these workers have access to their high-quality services.

Recommendation 13: The General Assembly should take action to improve the compensation for consumer-directed services attendants and to provide a living wage that is consistent with the national average and commensurate with the value of the work performed. Further, the General Assembly should consider implementing regular Cost-of-Living Adjustment (COLA) increases to the personal attendant rate to address the challenges related to low wages, high turnover rates, inflation and workforce shortages in the home care industry.

Family Members

Having a family member act as the EOR, or as a personal attendant, can be a very positive experience for some people and a not-so-positive experience for others. This is not surprising, given the scope and variety of individual circumstances that exist. What is clear is that flexibility and safeguards are needed to ensure the choice and preferences of the person using CD services are the primary consideration.

The Department of Medical Assistance Services (DMAS) 95B form (Appendix B) is for individuals who are seeking to become an Employer of Record (EOR), often a family member, for a participant enrolled in the CD services. According to DMAS, the purpose of the DMAS 95B form is to ensure that the EOR is suitable for the role and can effectively manage the participant's services and supports. The DMAS 95B form is considered "a good idea" to complete. However, it is not required. The services facilitator training module 2B states:

"Once you have explained an EOR's role, responsibilities and rights, it is a good idea to ask the proposed EOR to complete the DMAS-95B. Although this form is designed for family members who are becoming an EOR, it can also be used for non-family member EORs."

The DMAS 95B questions allow the potential EOR to think about important topics, such as: i) whether the EOR and the individual generally agree on how services will be provided; (ii) how the EOR would be able to determine the quality of work the attendant performs; (iii) how the EOR would address a situation in which the attendant failed to fulfill his or her job duties adequately, and the EOR should give some examples of such situations; (iv) whom the EOR would contact if the individual were injured or mistreated by the attendant and what other actions would be taken, even if the attendant is a family member. By requiring this form to be completed, DMAS can improve transparency and consistency in the CD services program and help to ensure that qualified and appropriate EORs support individuals receiving CD services.

Recommendation 14: The Department of Medical Assistance Services (DMAS) should establish a policy that requires a services facilitator to complete, and review annually, the DMAS 95B form in cases where a family member of an adult who uses CD services requests to become the Employer of Record (EOR). This policy would ensure that the services facilitator reviews the family member's qualifications and suitability for the EOR role and helps to mitigate potential conflicts of interest that may arise in these situations.

Since June 2020, legally responsible persons, such as parents of minor children and spouses, have been able to be paid providers of personal assistance services under the CD services program. Families have reported that this change has had a significant positive impact on their lives. Data from DMAS shows that during April 2020-October 2020, Virginia had 1,757 legally responsible individuals employed to provide care through CD services.

Traditionally, Virginia has not allowed legally responsible persons to be paid providers of CD services. This policy was temporarily modified during the Covid-19 public health emergency through the DMAS Appendix K submission to the federal Centers for Medicare and Medicaid Services (CMS). Appendix K allows states to make temporary modifications to certain Home and Community-Based Services (HCBS) waiver requirements without seeking formal approval from CMS during emergencies and disasters. Overall, the temporary modification provided by Appendix K has allowed families to access critical services during a challenging time and has helped to improve the well-being of individuals who rely on CD services, overall quality of life for families, and alleviate some of the stress caused by workforce shortages.

The flexibility provided by Appendix K has been especially important for families who may not feel comfortable with additional individuals coming into their homes. By allowing legally responsible persons to serve as paid providers, families can better manage exposure risks and maintain a safer environment for their loved ones.

Additionally, if Virginia makes the flexibility permanent, the Commonwealth would reduce the financial burden on parents and spouses whose caregiving responsibilities often mean they cannot be employed outside the home. Altogether, parent caregivers of minor children with disabilities across the United States forfeit about \$17.6 billion in earnings per year, according to a 2017 study (Randi, 7). The National Council on Disability (NCD) found that “Even before COVID-19, some family caregivers reported experiencing...short- and long-term financial consequences to devoting significant time to caregiving...Furthermore, studies reported that over 50 percent of family caregivers had jobs that pay hourly wages...suggesting that taking unpaid time off threatened their economic stability.” Recognizing the benefit of allowing families as paid caregivers, the NCD recommended that states and state Medicaid agencies should implement permanent policies that encourage and facilitate paid family caregiving (NCD, 134).

Recently, DMAS submitted a renewal application for the Family and Individual Supports Waiver to CMS. The renewal application removed the ability for legally responsible persons, such as

parents and spouses, to serve as the paid provider of CD services. Instead, DMAS will require that legally responsible persons be employed by an agency, effectively imposing the agency-directed model. This change may limit the ability of families to choose who provides their loved ones with needed services and supports under CD services, which could have a negative impact on individuals and families.

Many states have allowed legally responsible persons, such as parents and spouses, to serve as paid caregivers under their CD programs and have seen positive results from this flexibility. As such, it is worth considering the benefits of making this change permanent in Virginia's CD services program.

Recommendation 15: The Department of Medical Assistance Services (DMAS) should develop clear and comprehensive criteria that allow legally responsible persons to serve as paid attendants under Consumer-Directed Services while ensuring that appropriate safeguards are in place. These criteria should consider the unique needs and circumstances of the individual receiving services, as well as any potential conflicts of interest or concerns related to attendant qualifications or suitability.

APPENDIX A-1: Survey Questions

Share Your Experience with Medicaid Consumer-Directed Services

Help us help you! Do you use Medicaid consumer-directed services? Do you help someone use consumer-directed services? Consumer-directed services allow you to employ your own staff. If so, please share your experience!

Your information will help the Virginia Board for People with Disabilities recommend improvements to the service. Survey responses will help the Board identify what is working well, where improvements are needed, and develop recommendations.

Instructions:

- Consumer Directed Services is referred to as CD Services through the survey. Consumer directed services refers to personal assistance, companion, and/or respite services where the individual has option to hire, train, and supervise their own personal attendants.
- Survey questions are worded from the perspective of the person who receives CD Services e.g. “I, you, your”.
- It is recommended that the Employer of Record (EOR) complete the survey. If the EOR is someone other than the person with a disability, the EOR is strongly encouraged to include the person with a disability in the completion of the survey. It is acceptable for someone other than the EOR to complete the survey with the person who uses CD Services.
- **A paid support person should NOT complete this survey.**

Please plan to spend up to X minutes on the survey **by the end of Monday, March 21.** Your feedback will be **anonymous.**

For help, or copies of the survey in an alternative format, please contact Clare Huerta at 804-786-9380 or Clare.Huerta@vbpd.virginia.gov.

1. Do you use Consumer Directed (CD) services or are you the EOR of a person who uses CD services? (Note: end survey if a “No” or “I am not sure” response. Do not go to Demographic Data.)

*Consumer Directed (CD) services are personal assistance, companion, and/or respite services where the individual has option to hire, train, and supervise their own personal attendants. These services are available in the Developmental Disabilities Waivers (Community Living and Family and Individual Supports), the CCC Plus Waiver, EPSDT and the Medicaid Works Program.

- Yes
- No
- I am not sure

2. I access CD Services through...

- Developmental Disabilities Waiver: Community Living
- Developmental Disabilities Waiver: Family and Individual Supports
- Commonwealth Coordinated Care Plus (CCC Plus) Waiver
- Early and Periodic Screening, Diagnostic, and Treatment (EPSDT)
- Medicaid Works Program
- I'm not sure

3. Who is completing this survey?

- The individual participating in CD services
- Family member who is not paid with the person who receives CD services
- A natural support who is not paid, like a friend, with the person who receives CD services
- Employer of Record (if this person is different from the person participating in CD services)
- Other (fill in)

4. Who serves as the CD Services Employer of Record?

- The individual participating in CD Services
- Family member, for example a parent, grandparent, or sibling
- Other natural support, for example a friend or neighbor
- Other (fill in)
- I'm not sure

5. How long have you been participating in CD Services?

- Less than one year
- One to two years
- Three to five years
- Six to ten years
- More than 10 years
- I'm not sure

6. What CD Services do you use? (check all that apply/must check at least 1):

- Personal Assistance Services
- Companion Services
- Respite Services

7 (a/b). (if Q2 does not equal one of the DD waiver options) In addition to CD Services, what other services do you use (check all that apply)

- Agency-directed personal assistance, companion or respite services

- Individual Supported Employment Services
- Group Supported Employment Services
- Other?
- None

(a/b). (if Q2 = one of the DD waiver options) In addition to CD Services, what other services do you use (check all that apply)

- Agency-directed personal assistance, companion or respite services
- Individual Supported Employment Services
- Group Supported Employment Services
- Group day services
- In home services
- Community Engagement services
- Other?
- None

8. Living Situation:

- Independently in my own home
- Independently with roommate
- With family member or caregiver

Your Benefits and Challenges with Consumer-Directed Services

9. What benefits have you experienced using CD services? (Select all that apply)

- Truly get to select who works for me
- Hired people I know
- Obtained a higher quality staff
- Hired people who share my interests
- Staff are reliable
- Hired family members as staff and paid them
- Have a better cultural match with staff
- Reduced staff turnover
- Scheduled staff hours based on my needs and preferences
- I have more control over who provides my services.
- Other (fill in)
- I'm not sure
- I have not experienced any benefits related to staff

10. How has your quality of life changed, if at all, because of directing your own services? (Select all that apply)

- I have a better quality of life.
- I have more independence
- I have more control over my daily schedule.
- I have a plan that is flexible and meets my specific needs.

- I feel more empowered.
- I spend more time doing things outside my home
- I have an improved relationship with family and friends.
- I have a reduced stress level.
- I live where I choose.
- I have my needs and preferences respected.
- Other: (write in)
- No change

11.

- Have you had challenges with managing the paperwork for your CD services?
 - not challenging
 - somewhat challenging
 - very challenging
 - I'm not sure
- Have you had challenges with reduction in the number of authorized hours for your CD services?
 - not challenging
 - somewhat challenging
 - very challenging
- Have you had challenges with using Electronic Visit Verification (EVV) for your CD services?
 - Not challenging
 - Somewhat challenging
 - Very challenging
 - I'm not sure
- Have you had challenges with reimbursement process for CD services providers?
 - Not challenging
 - Somewhat challenging
 - Very challenging
- Have you had challenges working with your services facilitator?
 - Not challenging
 - Somewhat challenging
 - Very challenging
- Have you had challenges with controlling employment decisions related to your CD Services?
 - Not challenging
 - Somewhat challenging
 - Very challenging
- Have you had challenges with the pay rate for CD attendants?
 - Not challenging
 - Somewhat challenging
 - Very challenging

12.

- Have you had challenges with finding staff for your CD services?
 - Not challenging
 - Somewhat challenging
 - Very challenging

- Have you had challenges with training staff for your CD services?
 - Not challenging
 - Somewhat challenging
 - Very challenging

- Have you had challenges with disciplining staff for your CD services?
 - Not challenging
 - Somewhat challenging
 - Very challenging

- Have you had challenges with keeping or retaining staff for your CD services?
 - Not challenging
 - Somewhat challenging
 - Very challenging

- Have you had challenges with training and monitoring staff for your CD services?
 - Not challenging
 - Somewhat challenging
 - Very challenging

- Have you had challenges with cultural differences with staff for your CD services?
 - Not challenging
 - Somewhat challenging
 - Very challenging

- Have you had challenges with scheduling staff when you need them for your CD services?
 - Not challenging
 - Somewhat challenging
 - Very challenging

Optional Comment box for additional information -

Tell us more about challenges or benefits you have had with CD Services. This question is optional.:
--

Your Experience with Your Services Facilitator

The following questions ask about your services facilitator. A services facilitator is the person who supports the individual in consumer-directing services. The services facilitator trains the EOR on the responsibilities of being an employer and how to manage attendants.

13 (a/b). (If Q2 is not one of the DD waiver options) I communicate with my services facilitator

- Not enough
- Just the right amount
- Too much

(a/b). (If Q2 = one of the DD waiver options) I communicate with my services facilitator

- Not enough
- Just the right amount
- Too much
- Not applicable, I do not have a services facilitator (skip logic: This answer skips to Q15)

14.

- Did your services facilitator help you hire your staff?
 - Did not help at all
 - Helped some
 - Helped a lot
 - I'm not sure
- Did your services facilitator help train you on how to be an employer?
 - Did not help at all
 - Helped some
 - Helped a lot
 - I'm not sure
- Does your services facilitator help you direct your services?
 - Does not help at all
 - Helps some
 - Helps a lot
 - I'm not sure
- Did your services facilitator help you develop a service plan that meets your needs?
 - Did not help at all
 - Helped some
 - Helped a lot
 - I'm not sure
- Does your services facilitator help you maintain your health and well-being?
 - Does not help at all
 - Helps some
 - Helps a lot
 - I'm not sure

15. Which resources have helped you find staff? (check all that apply)

- Services facilitator
- Friends
- Immediate/extended family
- Other people with disabilities or their families
- Advertisements
- Care Coordinator (available for people receiving services through Managed Care Organizations and Commonwealth Coordinated Care Plus waiver)
- Support Coordinator (available for people receiving services through the Developmental Disability waiver)
- Fiscal employer agent (F/EA)
- Social media
- Employer of Record (EOR) Manual
- Other
- I'm not sure
- I did not receive help with finding staff

Optional Comment box for additional information -

Tell us more about how you have found staff. This question is optional.:

Meeting Your Needs

16. The number of hours of CD services I receive each week is...

- Too much
- Not enough
- Just right
- I'm not sure

17. What support is provided by family/friends (check all that apply)

- personal care
- community living
- grocery shopping
- transportation
- managing money
- medical
- home maintenance needs
- coordination/paperwork
- recreation and socialization
- Other (fill in)
- I do not receive support from my family/friends

18. My experience with CD services would be improved if (check all that apply):

- My services facilitator was more accessible
- There were more resources available to train my staff
- There were more resources available to recruit staff

- The paperwork process was easier to manage
- Person-centered practices were followed during the planning process
- My attendant/staff were paid on time
- Other (fill in)
- Nothing would improve my experience with CD services

Optional Comment box for additional information -

Is there anything else we should know about your experience with CD Services? This question is optional:

About You: **The following questions are optional.** Your answers are anonymous. We collect this information to help us understand who is taking this survey.

19. What is your age (in years)? This question is optional. [numeric response]

20. What is your gender? This question is optional.

- Female
- Male
- Non-binary
- Prefer not to say

21. What is your race/ethnicity? This question is optional.

- Asian
- Black or African American
- Hispanic or Latino
- Native American or Native Alaskan
- Native Hawaiian or Pacific Islander
- White/Caucasian
- Two or more races
- Some other race
- Unknown
- Prefer not to say

22. Where do you live? This question is optional.

- Central Virginia
- Northern Virginia
- Southwest Virginia
- Tidewater Virginia
- I'm not sure
- Prefer not to say

Thank you for completing the survey!

APPENDIX A-2: Survey Analysis

Consumer Directed Services Survey Results

Who answered the survey?

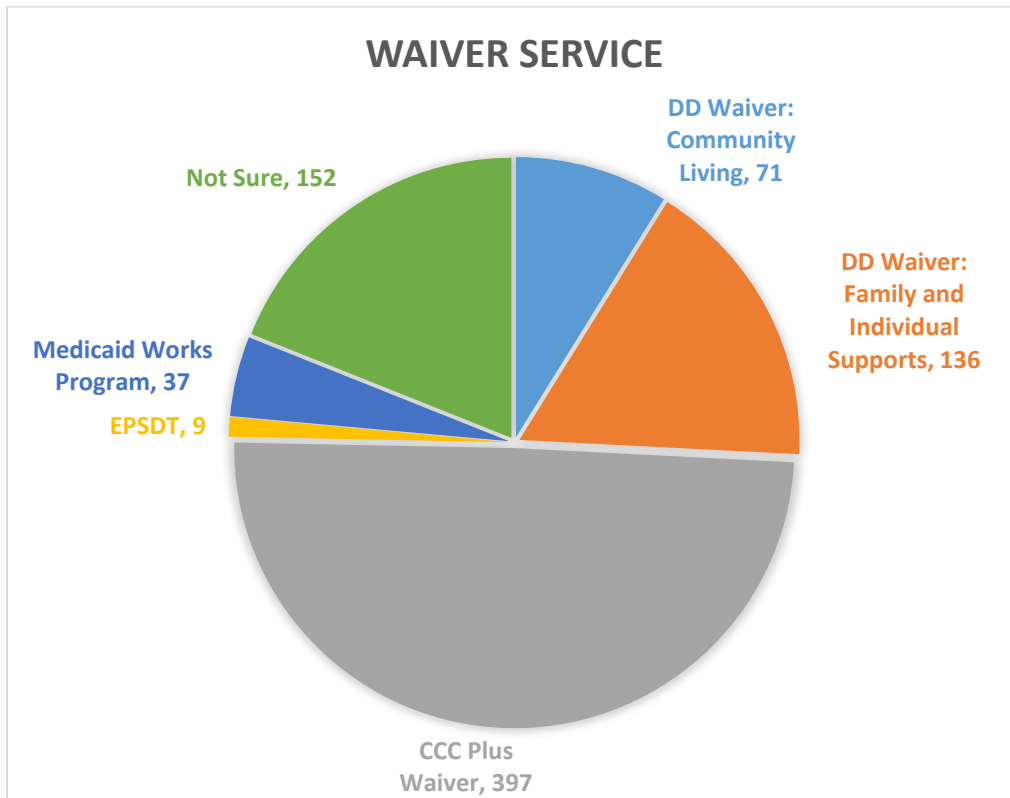
Consumer-Directed Services User Characteristics

928 people accessed the survey. 802 people completed at least the questions about services (how they/the individual accesses CD services, who answered the survey, who served as employer of record). Characteristics of Services Users are presented in Table 1; highlights and figures are below.

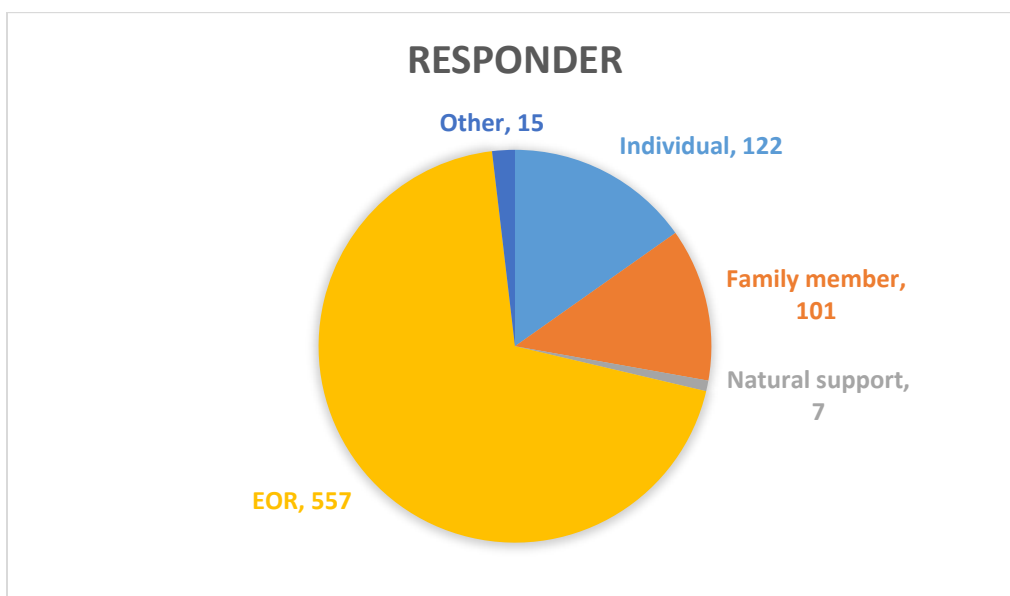
Table 1.
CD Services User Characteristics

	N (valid %)
CD Services (N=802)	
DD Waiver: Community Living	71 (8.9)
DD Waiver: Family and Individual	136 (17)
Supports	
CCC Plus	397 (49.5)
EPSDT	9 (1.1)
Medicaid Works	37 (4.6)
Not sure	152 (19.0)
Responder Type (N=802)	
Individual using CD Services	122 (15.2)
Family member	101 (12.6)
Other natural support	7 (.9)
EOR	557 (69.5)
Other	15 (1.9)
Employer of Record (N=802)	
Individual	138 (17.2)
Family	586 (73.1)
Other natural support	38 (4.7)
Not sure	17 (2.1)
Other	23 (2.9)
How long using CD Services (N=802)	
Less than one year	76 (9.5)
1-2 years	131 (16.3)
3-5 years	228 (28.4)
6-10 years	207 (25.8)
More than 10 years	136 (17.0)
Not sure	24 (3.0)
Living Situation (N=764)	
Independently in own home	184 (24.1)
Independently with roommates	15 (2.0)
With family or caregiver	565 (74.0)

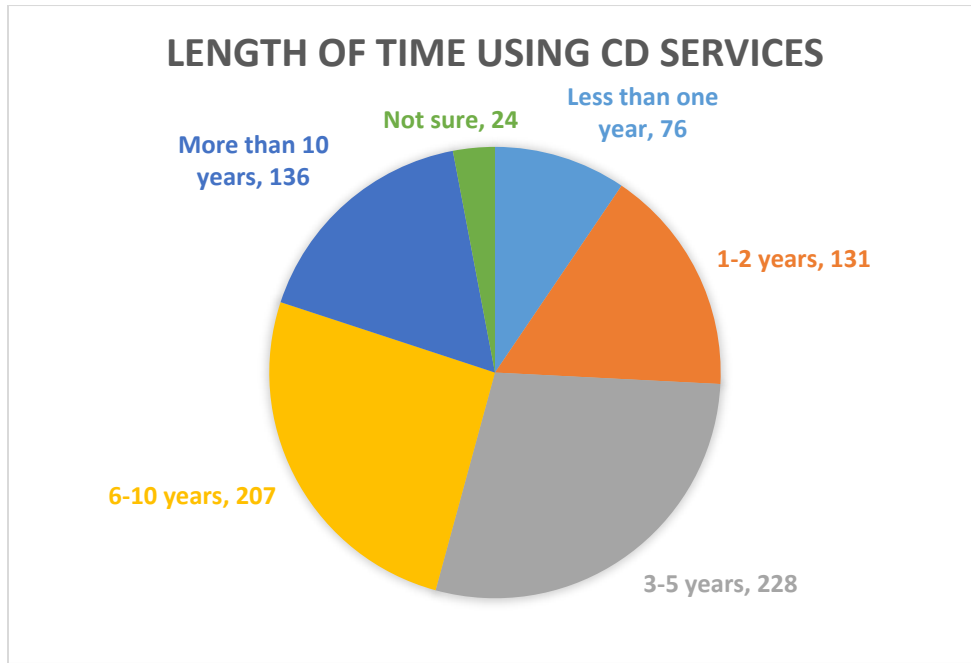
About half of respondents accessed CD services through the CCC Plus Waiver (49.5%). The second most popular category was 'Not Sure' (19%), followed by the Family and Individual Services Waiver (17%).



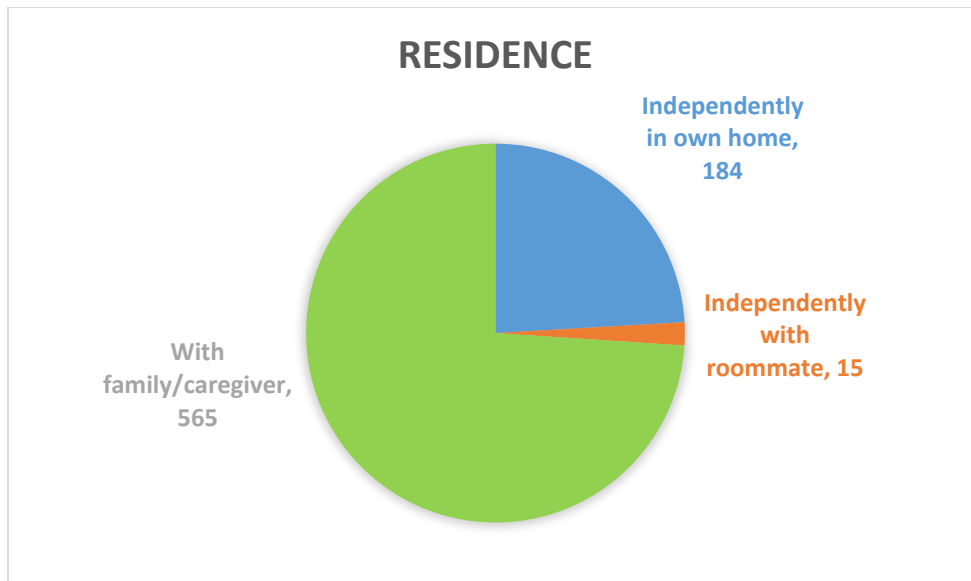
Most respondents were the Employer of Record (EOR; 69.5%). A smaller number of respondents were the individual using CD Services (15.2%) or a family member of the individual who was not the EOR (12.6%).



Most respondents had been using CD services for 3-5 years (28.4%) or 6-10 years (25.8%).



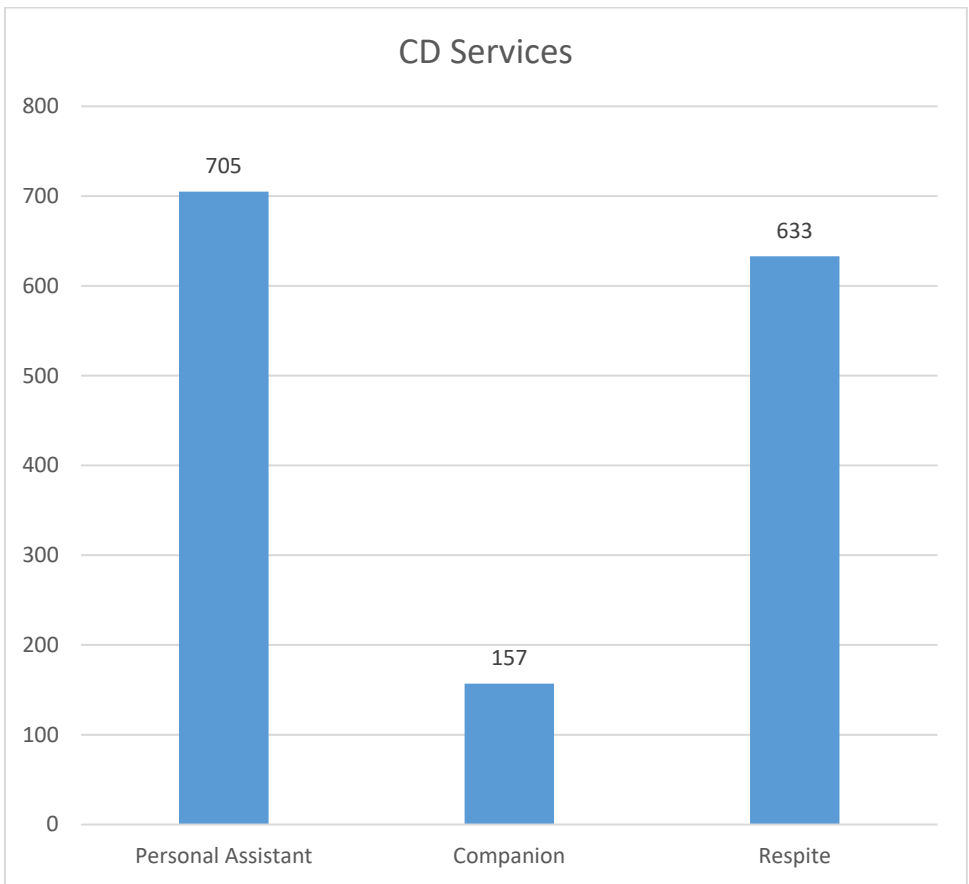
Most respondents lived with family or a caretaker (74%) or independently in their own home (24.1%).



Respondents were most likely to use personal assistant (76%) and respite (68.2%) services (note that services were not mutually exclusive and some respondents used all services).

Services	N (%)
CD Services	
Personal Assistant	705 (76.0%)

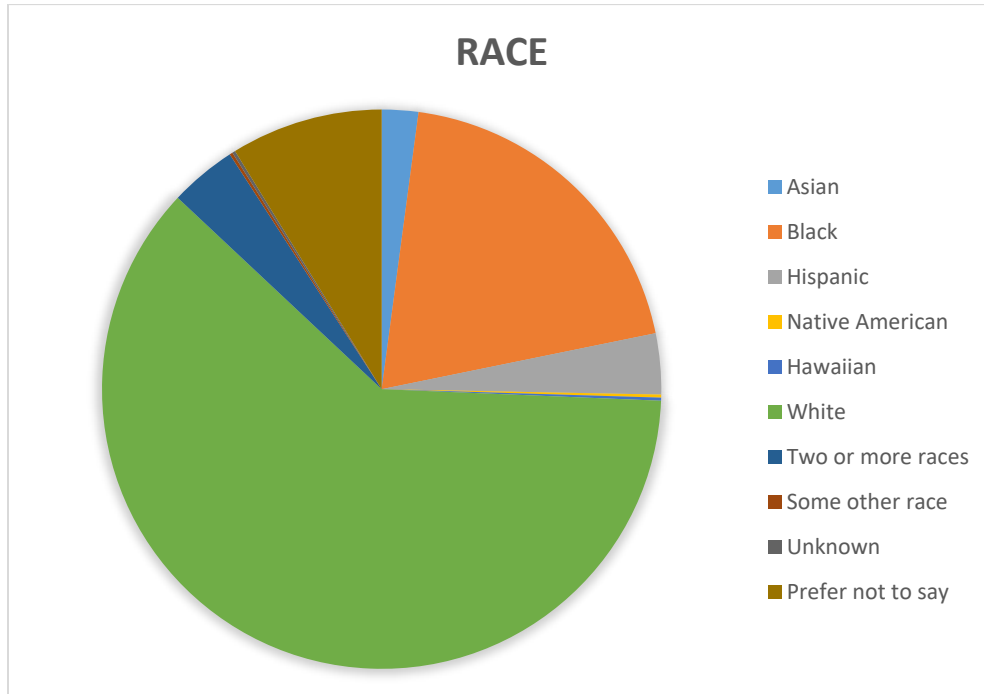
Companion	157 (16.9%)
Respite	633 (68.2%)
Other Services	
Other Non-DD Waiver Services	N (%)
Agency-Directed	154 (16.6)
Individual employment	49 (5.3)
Group employment	5 (.5)
None	82 (8.8)
Other DD Waiver Services	
Agency directed	38 (4.1)
Individual employment	19 (2.0)
Group employment	2 (.2)
Group Day	25 (2.7)
In home services	58 (6.3)
Community engagement	13 (1.4)
None	82 (8.8)



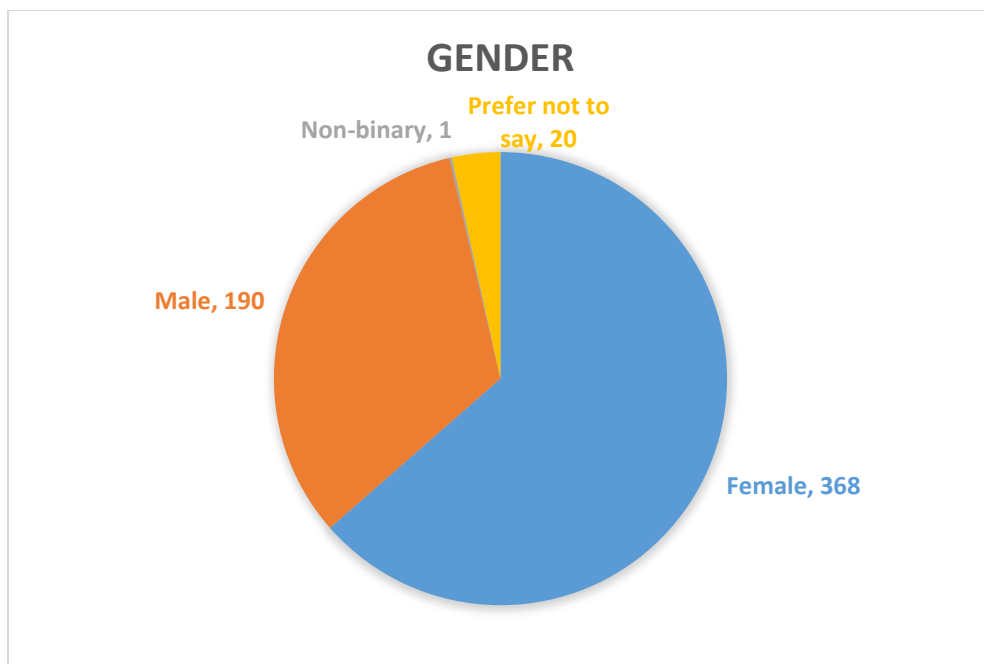
Demographics

Full demographic characteristics are presented in Table 2. Highlights and graphs are below.

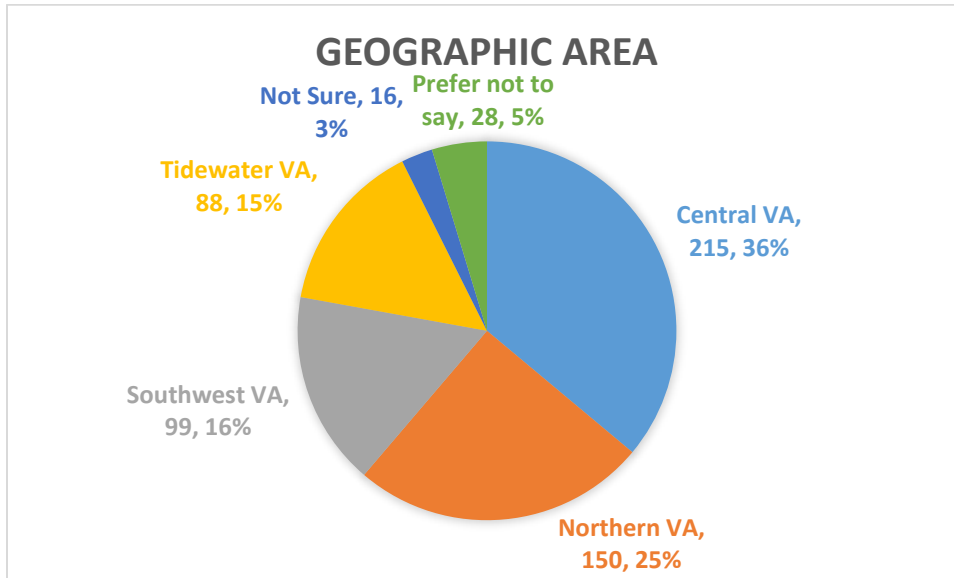
Respondents were mostly White (61.3%) and Black (19.7%).



Respondents were mostly female (63.6%). Non-binary was offered as an option for gender and was selected by 1 participant (.2%).



Respondents came from all over Virginia, with most respondents living in Central Virginia (36.1%) and Northern Virginia (25.2%).



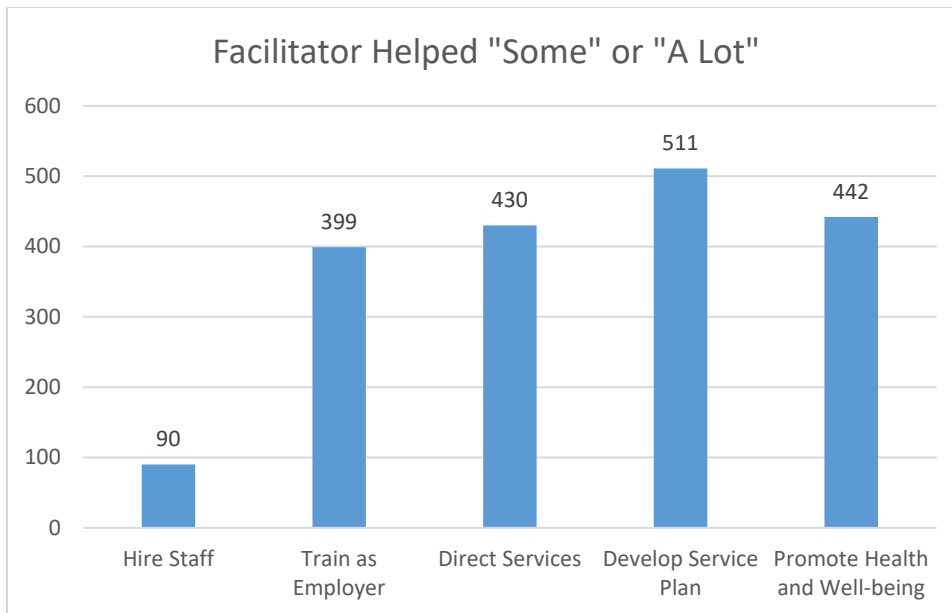
Satisfaction with Consumer-Directed Services and Services Facilitator

Services Facilitator	N (valid %)
I see my services facilitator (Non-DD waiver) (N=500)	
Not enough	63 (12.6)
Just the right amount	419 (83.8)
Too much	18 (3.6)
I see my services facilitator (DD waiver) (N=189)	
Not enough	14 (7.4)
Just the right amount	156 (82.5)
Too much	16 (8.5)
I don't have a services facilitator	3 (1.6)
Helped hire staff (N=682)	
Did not help at all	422 (61.9)
Helped some	170 (24.9)
Helped a lot	73 (10.7)
Not sure	17 (2.5)
Helped train as an employer (N=682)	
Did not help at all	258 (37.8)
Helped some	237 (34.8)
Helped a lot	162 (23.8)
Not sure	25 (3.7)
Helped direct services (N=682)	

Did not help at all	206 (30.2)
Helped some	257 (37.7)
Helped a lot	173 (25.4)
Not sure	46 (6.7)
Helped develop a plan (N=682)	
Did not help at all	134 (19.6)
Helped some	236 (34.6)
Helped a lot	275 (40.3)
Not sure	37 (5.4)
Helped promote health and wellbeing (N=682)	
Did not help at all	198 (29.0)
Helped some	244 (35.8)
Helped a lot	198 (29.0)
Not sure	42 (6.2)
Satisfaction with hours	
The number of CD hours per week is (N=666)	N (valid %)
Not enough	287 (43)
Just right	342 (51.3)
Too much	3 (.45)
Not sure	34 (5.1)

While 51.3% of respondents reported that they had “just the right amount” of hours, 43% said that they had “not enough” hours. Only 3 respondents reported having “too many” hours.

Participants were most likely to report that their services facilitator “helped some” or “helped a lot” with developing a service plan, promoting health and wellbeing, and directing services. Fewer respondents reported that their facilitator helped them hire staff.



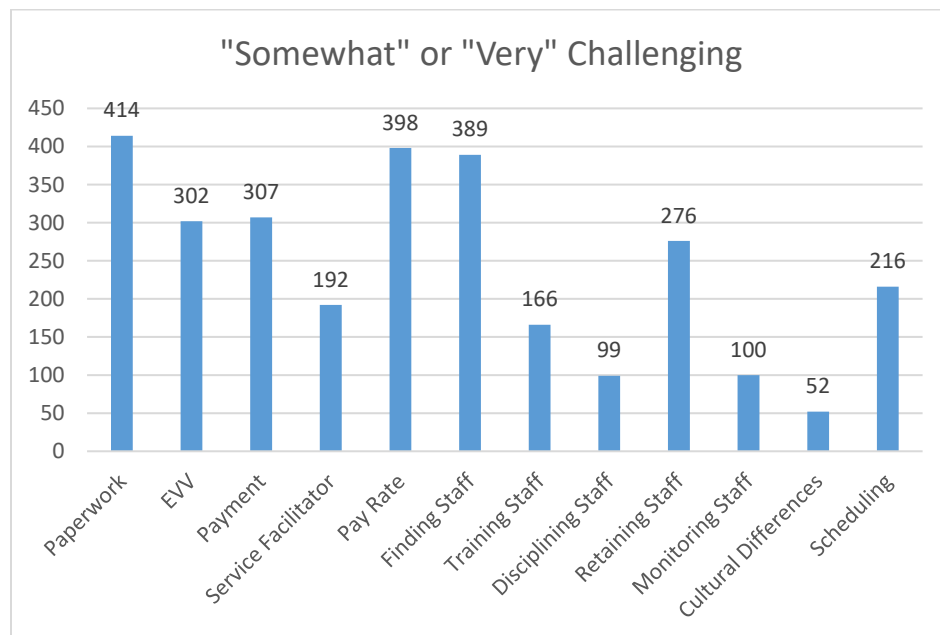
Challenges with Services

Challenges with CD Services

	N (valid %)
Paperwork (N = 699)	
Not challenging	259 (37.1)
Somewhat challenging	279 (39.9)
Very challenging	135 (19.3)
Not sure	26 (3.7)
EVV (N=699)	
Not challenging	229 (32.8)
Somewhat challenging	198 (28.3)
Very challenging	104 (14.9)
Not sure	47 (6.7)
I don't use EVV	121 (17.3)
Payment (N=699)	
Not challenging	392 (42.2)
Somewhat challenging	216 (23.3)
Very challenging	91 (9.8)
Not sure	0 (0)
Facilitator (N=687)	
Not challenging	495(72.1)
Somewhat challenging	139 (20.2)
Very challenging	53 (7.7)
Not sure	0 (0)
Pay Rate (N=699)	
Not challenging	301 (43.1)
Somewhat challenging	198 (28.3)
Very challenging	200 (28.6)
Not sure	0 (0)
Finding Staff (N=690)	
Not challenging	301 (43.6)
Somewhat challenging	176 (25.5)
Very challenging	213 (30.9)
Not sure	0 (0)
Training Staff (N=690)	
Not challenging	524 (75.6)
Somewhat challenging	115 (16.7)
Very challenging	51 (7.4)
Not sure	0 (0)
Disciplining Staff (N=690)	
Not challenging	591 (85.7)
Somewhat challenging	76 (11.0)
Very challenging	23 (3.3)
Not sure	0 (0)

Retaining Staff N=690)	
Not challenging	414 (60.0)
Somewhat challenging	166 (24.1)
Very challenging	110 (15.9)
Not sure	0 (0)
Monitoring Staff (N=690)	
Not challenging	590 (85.5)
Somewhat challenging	84 (12.2)
Very challenging	16 (2.3)
Not sure	0 (0)
Cultural Differences (N=690)	
Not challenging	638 (92.5)
Somewhat challenging	44 (6.4)
Very challenging	8 (1.2)
Not sure	0 (0)
Scheduling (N=690)	
Not challenging	474 (68.7)
Somewhat challenging	162 (23.5)
Very challenging	54 (7.8)
Not sure	0 (0)

Respondents were most likely to report that the paperwork associated with CD services, the pay rate for staff, and finding staff were “somewhat challenging” or “very challenging.” The fewest respondents reported that cultural differences and disciplining staff were “somewhat” or “very challenging.”



Benefits to CD Services

Note—because of the survey format it's not possible to know if people didn't select an item because they disagreed with it or if they skipped the question. The percent reported is based on total survey responses.

Benefits: 689 people reported at least one benefit from CD services, 15 said they did not have any benefits, 224 did not select any option.

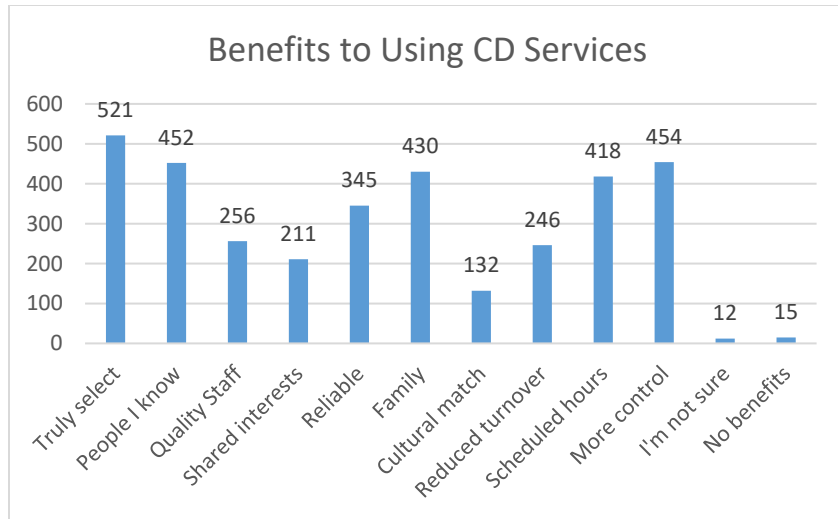
Quality of life: 624 reported at least on quality of life improvement, 80 said their quality of life did not change, 224 did not select any option.

Unpaid supports: 589 people reported receiving at least one type of support from friends/family, 64 said they did not receive any supports, 275 did not select any option.

Because the numbers of missing responses are so similar, not answering may mean that the respondent skipped this question, rather than passively indicating no benefits/quality of life changes/supports.

Benefits to CD Services	
	N (%)
Truly select staff	521 (56.1)
Hire people I know	452 (48.7)
High quality	256 (27.6)
Shared interests	211 (22.7)
Reliable	345 (37.2)
Hire family	430 (46.3)
Cultural match	132 (14.2)
Reduced turnover	246 (26.5)
Staff hours	418 (45.0)
Control	454 (48.9)
Not sure	12 (1.3)
No benefits	15 (1.6)

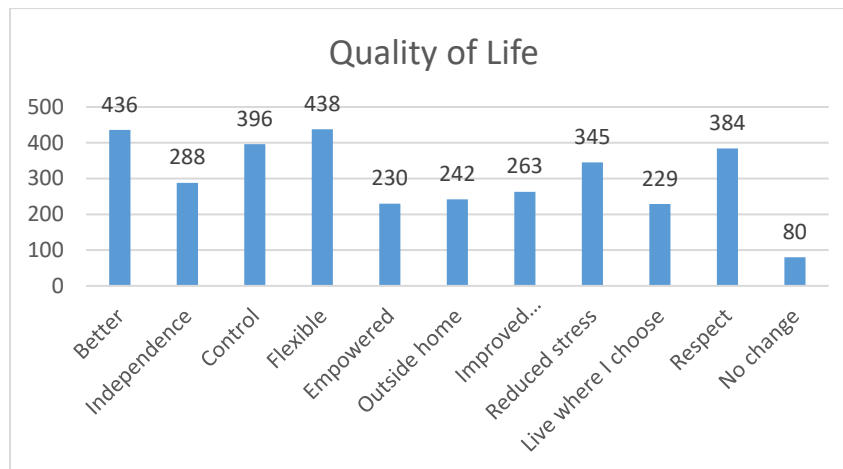
Respondents reported a number of benefits to using CD services. Respondents were most likely to say that truly selecting staff, increased control over services, hiring people they know, and hiring family were benefits to CD services. The fewest respondents reported a cultural match between themselves and their staff as a benefit. Only 15 (1.6%) respondents reported no benefits to CD services.



Quality of Life

	N (%)
QoL is better	436 (47.0)
Independence	288 (31.0)
Control	396 (42.7)
Flexible Plan	438 (47.2)
Empowered	230 (24.8)
Do more outside the home	242 (28.3)
Improved relationships	263 (28.3)
Reduced stress	345 (37.2)
Choose where to live	229 (24.7)
Needs are respected	384 (41.4)
No change	80 (8.6)

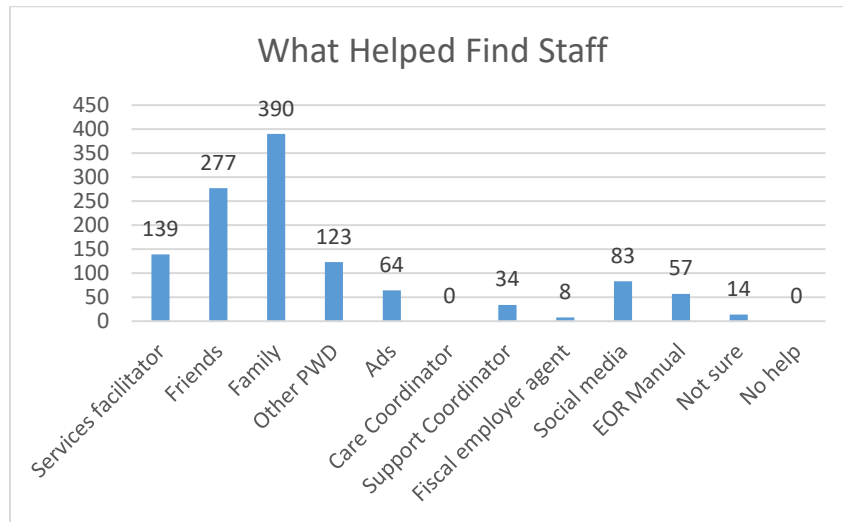
Respondents were most likely to report that their quality of life was better due to CD services and that they had a flexible plan that met their needs. 80 respondents (8.6%) reported that their quality of life had not changed since starting CD services.



What helped find staff?

	N (%)
Facilitator	139 (15.0)
Friends	277 (29.8)
Family	390 (42.0)
Other people with disabilities	123 (13.3)
Advertisements	64 (6.9)
Care coordinator	58 (6.3)
Support Coordinator	34 (3.7)
FEA	8 (.9)
Social media	83 (8.9)
EOR	57 (6.1)
Not Sure	14 (1.5)
No help	91 (9.8)

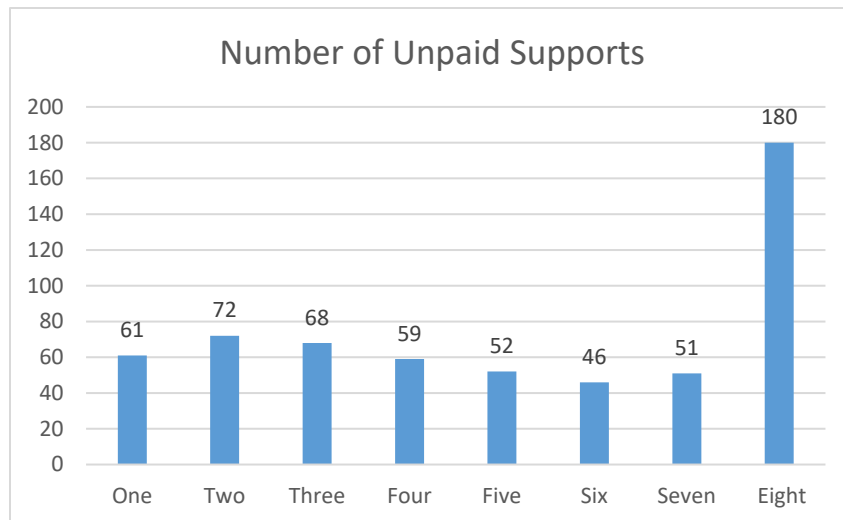
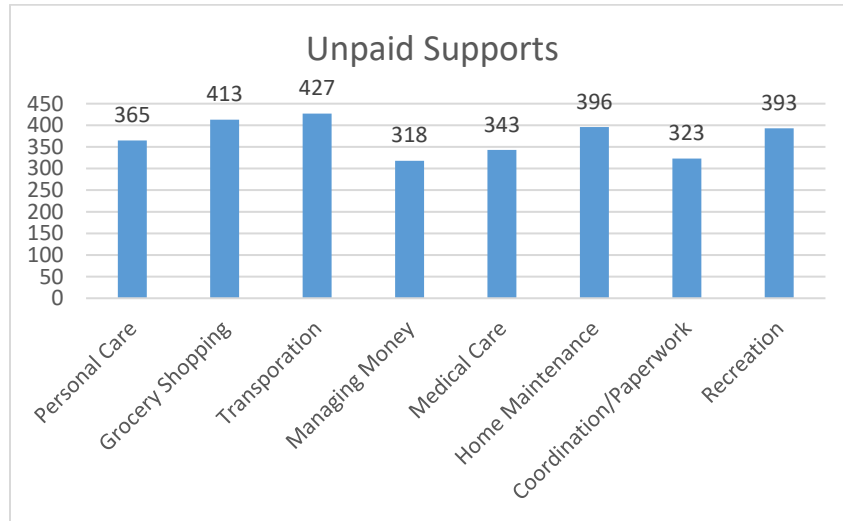
Respondents were most likely to report that family and friends helped them find staff and somewhat likely to report that their services facilitator and other people with disabilities helped them find staff.



Unpaid Support from Friends and Family

	N (%)
Personal Care	365 (39.3)
Grocery Shopping	413 (44.5)
Transportation	427 (46.0)
Managing Money	318 (34.3)
Medical	343 (37.0)
Home Maintenance	396 (42.7)
Coordination/Paperwork	323 (34.8)
Recreation	393 (42.3)

Respondents reported getting a great deal of unpaid support from friends and family, particularly with transportation, grocery shopping, home maintenance, and recreational activities.

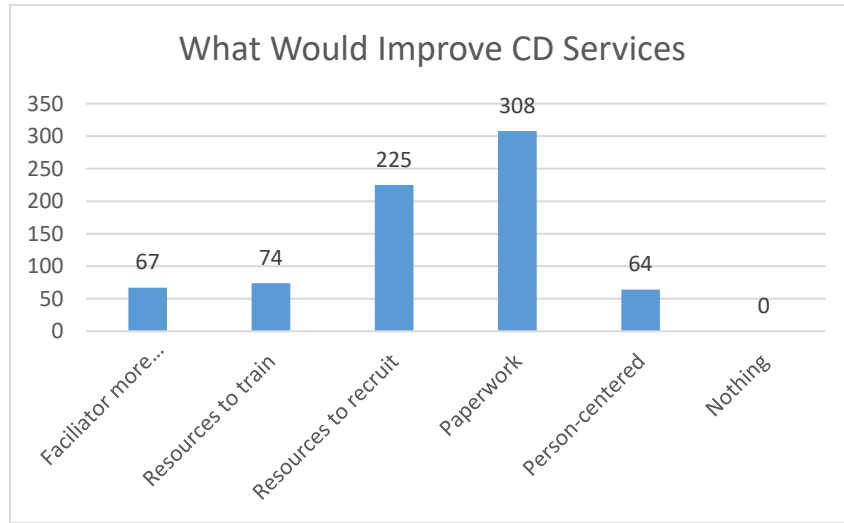


On average, participants reported receiving about five unpaid services from natural supports. 180 respondents reported that friends and family helped with all eight items related to this question.

What Would Improve CD Services?

	N (%)
Facilitator Was More Accessible	67 (7.2)
More Resources to Train Staff	74 (8.0)
More Resources to Recruit Staff	225 (24.2)
Easier Paperwork Process	308 (33.2)
More Person-Centered	64 (6.9)
Nothing	0 (0)

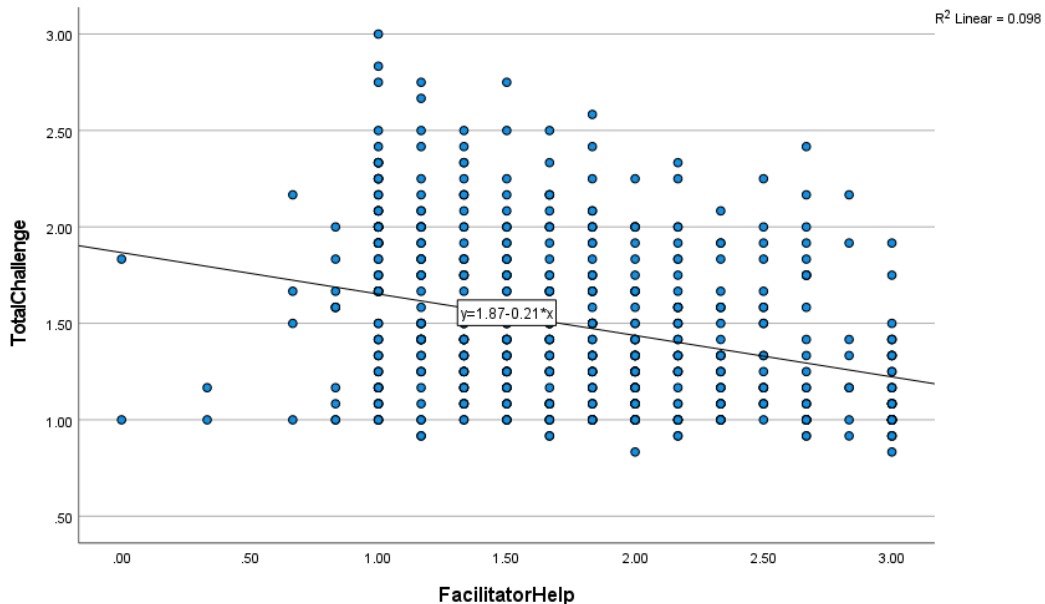
Respondents were most likely to report that simplifying the paperwork process and offering more resources to recruit staff would improve their experience with CD services.



Relationships between Variables

Challenges with CD Services

Support from one's services facilitator was negative associated with reported challenges ($r = -.312, p < .001$). Receiving more support from one's facilitator was associated with fewer overall challenges. Note that this is considered a weak relationship.



Unpaid support from friends and family was positively associated with reported challenges ($r = .318, p < .001$). Receiving more support from friends and family was associated with more overall challenges. Note that this is a fairly weak relationship.

This relationship was not expected—it was hypothesized that people who had more natural supports would have fewer challenges with CD services. However, there are several possible explanations. For example, people who use CD services who have higher involvement from family and friends may be more aware of and/or more vocal about the challenges they face.

Individuals who served as their own Employer of Record reported fewer overall challenges than people who had a family member as their EOR ($F = 4.89, p < .001$).

The same pattern held for paperwork ($\chi^2 = 26.45, df = 12, p = .009$), finding staff ($\chi^2 = 35.43, df = 12, p < .001$), and for pay rate ($\chi^2 = 32.06, df = 8, p < .001$). People who served as their own guardian were less likely to report that these tasks were ‘somewhat’ or ‘very’ challenging. There were no differences in level of challenge for payment, facilitator, training staff, disciplining staff, monitoring staff, or cultural differences.

The amount of help people received from their facilitator in hiring staff was significantly associated with how challenging they reported finding staff ($X^2 = 36.2, df = 6, p < .001$). People who reported that their facilitator ‘did not help at all’ or ‘helped some’ in hiring staff were more likely to report that finding staff was ‘very challenging.’ People who reported that their facilitator ‘helped a lot’ were more likely to report that finding staff was not challenging.

Similarly, question 15 asked how respondents found staff (multiple responses possible). People who reported that their facilitator helped them find staff were less likely to report that finding staff was ‘very challenging’ ($X^2 = 13.78, df = 2, p = .001$).

Total challenge was significantly associated with satisfaction with hours ($F = 7.37, p < .001$). People who reported not having enough hours also reported having more challenges with CD services.

The number of reported unpaid supports differed significantly by respondent type ($F = 4.54, p < .001$). EORs who answered the survey reported more unpaid services than people who completed the survey independently.

The number of unpaid supports also differed significantly by EOR ($F = 11.11, p < .001$). People who had a family member of ‘other’ as their EOR had significantly more unpaid supports than people who served as their own EOR.

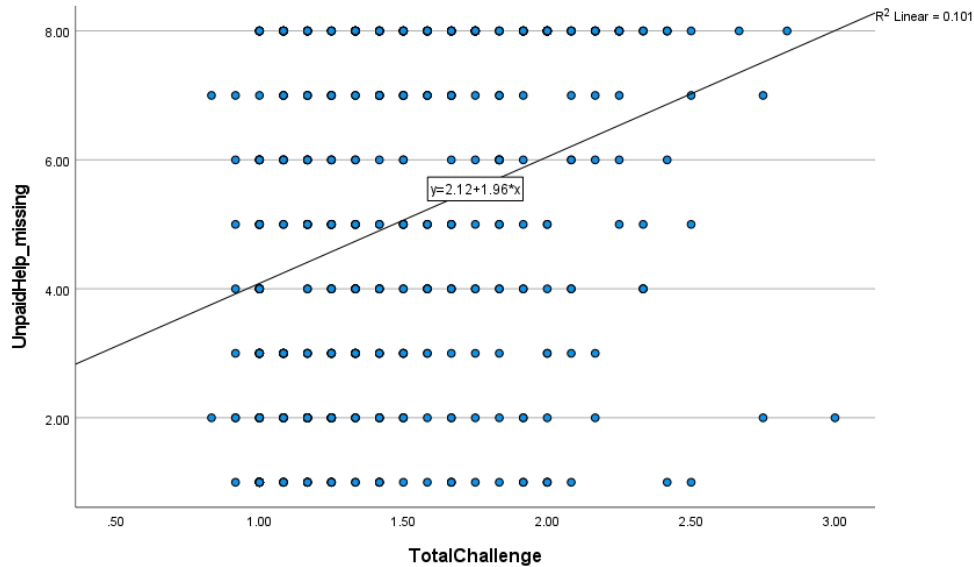
There were significant differences in the number of reported challenges by respondent type ($F = 4.27, p = .002$). Family members and EORs reported more challenges than individuals who answered on their own behalf. This could be because families/friends that are more involved in CD services may be more aware of and vocal about the challenges.

There was a possible difference in challenges by waiver type ($F = 2.65, p = .033$), but the exact relationships couldn’t be determined, likely due to a large portion of the sample receiving CD services through the CCC Plus waiver and 19% of respondents who were unsure of their waiver provider.

People who had used CD services for more than 10 years reported more challenges than people who had used CD services for less than one year or 1-2 years ($F = 3.65, p = .003$).

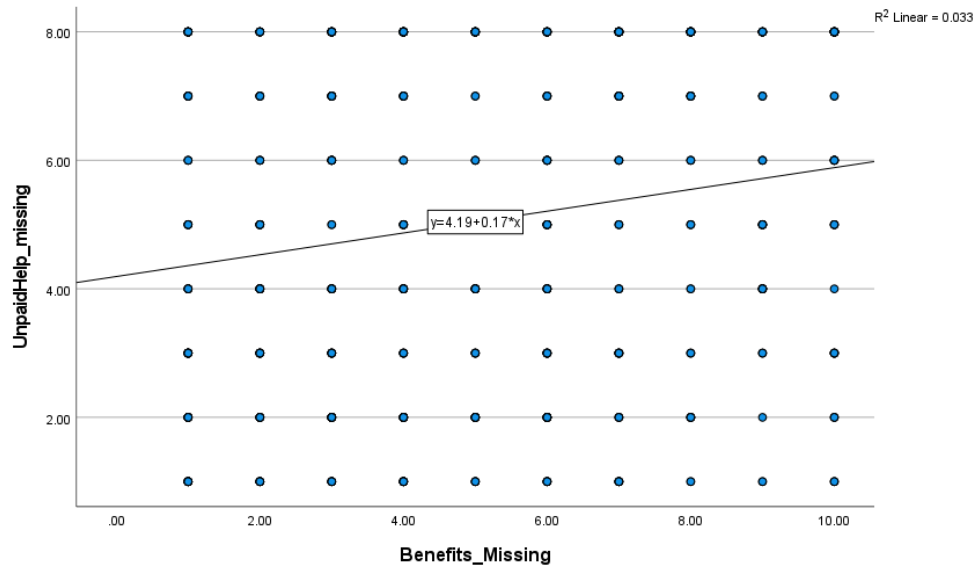
Region was significantly associated with reported challenges ($F = 5.80, p < .001$). People in Northern Virginia reported higher average challenges than people in Central Virginia, Southwest

Virginia, and people who were ‘Not sure.’ People in Central Virginia reported more challenges than people who were ‘not sure’ which region they lived in.



Benefits and Quality of Life

There was a *very* weak positive relationship between the number of unpaid supports and the reported benefits from CD services. More unpaid support from friends and family is associated with reporting more benefits from CD services ($r = .183$, $p < .001$). *Note—from a statistical standpoint there is little confidence in this relationship.*



There were no significant associations between satisfaction with hours and benefits, quality of life, or unpaid help.

There were no significant differences in quality of life improvements or reported benefits by EOR.

There were no significant differences in overall benefits or quality of life by respondent type. This suggests that we can be confident that proxy respondents (family, EOR, other) gave an accurate report of the benefits and quality of life improvements the individual experienced.

There were no significant differences in benefits, quality of life improvements, or support from one's services facilitator by waiver type.

There were significant differences in how long someone had used consumer-directed services and the benefits they reported ($F = 3.2, p = .007$). People who had used CD services for more than 10 years reported more benefits than people who had used CD services for less than one year. Interestingly, people who had used CD services for more than 10 years also reported more challenges than people who had used CD services for less than one year or 1-2 years ($F = 3.65, p = .003$).

Unpaid Supports

There were significant differences in the number of unpaid supports a person received among participants who knew which waiver service they used ($F = 5.18, p < .001$). People who received services through the Medicaid Works program reported fewer unpaid supports than people who received services through the Community Living Waiver or the Family and Individual Supports Waiver. People who received services through the CCC Plus Waiver reported fewer unpaid supports than people using the Family and Individual Supports Waiver.

People who had used CD services for more than 10 years also reported getting more unpaid help from friends and family than people who had used CD services for less than one year or 1-2 years ($F = 3.03, p = .01$). Given the other relationships between unpaid supports, benefits, and challenges, this might be the most important variable to consider.

Analyses with race/ethnicity was not possible due to a lack of variation (mostly White respondents) and high missingness.

Conclusion

Friends and family are providing a great deal of support either officially, as the EOR, or unofficially, through unpaid supports.

While this survey doesn't ask about diagnoses or support needs, people with more significant disabilities may be less likely to serve as their own EOR. That is, people with more complex needs (intellectual disability, behavioral support needs, chronic health conditions, etc.) are likely to have a family member or other natural support as their EOR and, likely, answering this survey. Higher and more complex needs likely also make managing CD services more complicated. Finally, people with multiple disabilities or chronic health conditions likely need (and, based on this survey) receive support from the people around them.

Data Notes

Total Unpaid Help = count of the number of supports a person endorsed

Average Challenge = average score of the 12 items related to challenges with CD services

Facilitator Help = average score of the 6 items related to help provided by the services facilitator

Total Quality of Life: count of the number of quality of life improvements a person endorsed

Total Benefits: count of the number of benefits from CD services a person endorsed

*No response was counted as ‘missing’ data and was not included in analyses. That is, a person who did not endorse any questions related to quality of life *including* “my quality of life has not changed” was counted as having skipped the question, NOT as an indication that the person had not experienced quality of life improvements.

Statistical Notes

In the tables, N is the number of people who answered each question. Valid % means the percentage using N as the denominator (people who skipped the question were not included). For ‘select all’ questions, % was calculated using the total sample (928) as the denominator.

F, r, and X^2 are mathematical symbols used to label the results of statistical tests. The symbol used depends on the type of test (F is for ANOVA, r is for correlation, X^2 is for Pearson’s chi-square). Higher values indicate a stronger relationship. For correlations (r) 0 to .19 is considered very weak, .2 to .39 is considered weak, .4 to .59 is considered moderate, and .6 to .79 is considered strong. There is no defined cut off for F or X^2 .

P is a measure of the likelihood that a result occurred by chance. A p value less than .05 means that there is less than a 5% chance a relationship occurred by chance and is considered statistically significant. This means that we can be somewhat confident that we are observing a real relationship.

APPENDIX B: DMAS 95B

CONSUMER-DIRECTION SERVICES MANAGEMENT QUESTIONNAIRE (Questions to consider if you want to manage consumer directed (CD) services on behalf of a family member)

Recipient's Name (*Print*): _____ Medicaid ID #: _____

1. Do you and your family member who is going to receive CD services generally agree on how personal care will be provided?

2. How would you describe the concepts of personal care to the family member who needs personal care?

3. How will you be able to determine the quality of work the personal assistant/aide performs?

4. If an assistant/aide did not fulfill his/her job duties adequately, what would you do?

5. What are some examples of the assistant/aide not performing his/her job duties?

6. Who would you contact if your family member was injured or mistreated by the assistant/aide?

b. What type of action would you take if you were suspicious of mistreatment to your family member?

c. What actions would you take once that you have discovered that your family member was injured or mistreated by the assistant/aide, even if the aide is a family member?

b. Would you report an incident to Adult Protective Services, Child Protective Services, or another authority, even if the assistant/aide were a family member?

Yes No

7. Would there be a reason that a family member would be hired to be the assistant/aide? If so, what would be the reason? What efforts would you make to find non-family members to be assistant/aides before you hired a family member?

8. What is your experience providing services, hiring staff, or monitoring personal care services?

9. If your family member who is receiving CD services wants you to hire other individuals or fire an assistant/aide, could you and would you?

b. Would you fire a family member? _____

Print name of family member who requests managing services: _____
Check (✓) the box of the relationship that this person has with the recipient (must be one of the following):
<input type="checkbox"/> Legal Guardian <input type="checkbox"/> Spouse <input type="checkbox"/> Parent of a minor (under 18 yrs. old) <input type="checkbox"/> Adult Child (18 yrs old +)

Recipient's Name (Print): _____ Medicaid ID #: _____
Person completing this form (Print name): _____
Signature of person completing this form: _____ Date: _____
Service Facilitation Provider: _____

APPENDIX C: Acknowledgements

Agencies Providing Data and Information

Virginia Department of Behavioral Health & Developmental Services
Virginia Department of Medical Assistance Services

Stakeholders Interviewed

Maureen Hollowell, Virginia Association of Centers for Independent Living
Tonya Milling, Lucy Cantrell, The Arc of Virginia

CD Services Survey Development and Analysis

Seb Proban, Assistant Director of Research and Evaluation, The Partnership for People with Disabilities at Virginia Commonwealth University
Sarah Lineberry, MSW, PhD, Evaluation Associate, The Partnership for People with Disabilities at Virginia Commonwealth University

Consultant

Applied Self Direction - Boston, Massachusetts

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