



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

**Access to Information
for People with Disabilities
and their Family Members**



**Virginia Board for
People with Disabilities**



2022 Assessment of Access to Information for People with Disabilities and their Family Members

First edition

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

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Management Support Solutions Inc. (MSSI) is a consulting and technical assistance firm with expertise in publicly funded long-term services and support (LTSS). MSSI specializes in assessing, designing and implementing person-centered systems of support, including Medicaid funded Home and Community-Based Services (HCBS) for people with lifelong disabilities

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The Virginians with Disabilities Act § 51.5-33 directs the Virginia Board for People with Disabilities (VBPD), beginning July 1, 2017, to submit an annual report to the Governor, through the Secretary of Health and Human Resources, that provides an in-depth assessment of at least two major service areas for people with disabilities in the Commonwealth. In June 2021, the Board selected Access to Information for People with Disabilities and their Family Members as an area to be covered in a 2022 Assessment. The Board, as part of its authority and responsibility as a Developmental Disabilities (DD) Council under the federal Developmental Disabilities and Bill of Rights Act (42 U.S.C. § 15021-15029), is also required to complete a similar analysis as it develops and amends its federal State Plan goals and objectives.

In this Assessment, the Board seeks to assess the current availability and usefulness of culturally and linguistically tailored information on community services and supports to people with developmental disabilities and their families.

The information and data for this Assessment was obtained from a variety of sources, including state and federal agency websites and reports, interviews with stakeholders and state and local agency representatives, and various research activities including literature reviews and an environmental scan. We appreciate the assistance of the state agencies that provided information and clarification on the information and data obtained and oversight responsibilities relevant to their agencies. The policy recommendations contained within this Assessment were reviewed, discussed and finalized by an ad hoc committee of the Board and approved by the Board's Executive Committee on June 27, 2022.

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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 information access is intended to serve as a guide for policymakers who are interested in ensuring that people with disabilities can obtain information needed to access services and supports that enable community living. 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

Purpose of the Assessment

To identify the current **availability, usefulness, and accessibility** of culturally and linguistically tailored information on community services and supports to people with developmental disabilities and their families in Virginia.

For many years, Virginians with intellectual and developmental disabilities (I/DD) and their families have reported difficulty finding, understanding and using information related to community services and supports.

Challenges faced by people seeking information are compounded by the complexity of the service delivery system and the fragmentation of sources of information. Federally funded, state administered services rely on established Local Departments of Social Services (LDSS) and Community Services Boards/Behavioral Health Authorities, referred to as CSBs throughout this assessment, to distribute and maintain current information.

The assessment identified four areas (shown in the infographic below) in which improvements could result in increased access to useful information for people with I/DD and their families.



Key findings from each of these areas are summarized below, followed by the recommendations.

Available, Accessible and Useful Information

Information is frequently not easily located. When located, information is often highly technical with clinical terms making it difficult to understand. Many local websites are not accessible in accordance with federal requirements, and none of the local or state websites reviewed met the highest accessibility standards. Information is often not available in multiple formats to accommodate people’s varying linguistic and sensory communication needs and lacks contextual translation for languages other than English.

Multiple websites were identified that offer a searchable database of services available and information on eligibility processes. However, inconsistent information across these sites creates confusion for stakeholders. Websites with searchable database include the following:

- Department of Behavioral Health and Developmental Services (DBHDS) Developmental Disabilities Waiver website <https://www.mylifemycommunityvirginia.org/>
- Department for Aging and Rehabilitative Services (DARS) No Wrong Door website <https://easyaccess.virginia.gov/>
- Virginia 211 Human Service Access website <https://211virginia.org/consite/index.php>
- Department of Social Services (DSS) website for navigating and applying for assistance <https://commonhelp.virginia.gov/>
- Virginia Navigator Family of Websites (non-profit organization) <https://virginiannavigator.org/>

The most readily available information is focused on the rules of administering the system, which may be useful for service provider agencies, but is not useful to people with I/DD or families. The information people with I/DD and families considered most useful is provided by another person with lived experience and with whom trust has been established.

Many CSB websites do not provide translated information, forcing families to rely on inaccurate machine translation like Google Translate. Most families who speak languages other than English described their experience with machine translation as illogical or challenging to understand because the words, when taken out of context, can translate with very different meaning, further contributing to lack of understanding. For families who are not primary English speakers, requesting an institutional level of care is an example of translation confusion. Families report concern and alarm over requirements to declare they are seeking to place their family member in an institution. For people with distrust of government agencies, this requirement presents a significant barrier to accessing services.

System Capabilities: Knowledge and Skills of Staff

There are some state efforts to ensure that informational materials are up to date, but there are opportunities to further streamline and improve these efforts. The highly complex and frequently changing nature of Medicaid home and community-based services (HCBS) information requires constant attention of the agencies responsible for assisting individuals with I/DD and families to navigate the initial eligibility and application process. DBHDS has implemented numerous system improvements over the past several years, some in response to the Department of Justice (DOJ) Settlement Agreement and many at the Department's own initiative. DBHDS has the responsibility to ensure information and policy changes are clearly communicated and disseminated. The pace and volume of changes occurring makes it difficult to track all relevant communications. It is unclear if there are dedicated staff across the agency who are responsible for coordinating system-wide information updates in a comprehensive manner.

Staffing challenges at CSBs hinder their ability to provide up-to-date information. High turnover rates among intake and support coordination staff range from 0-75%, which results in staff who are less knowledgeable about the complex Medicaid rules. When these staff provide inaccurate information, it is left to the families and self-advocates to correct them. Families report feeling disrespected when pointing out contradictory information and feel particularly vulnerable when inquiring about inconsistent information between agencies.

There are opportunities to coordinate across CSBs. Rapidly changing information, procedures and documents causes each of the 40+ local agencies to update forms, manuals and instructions, often without enough time to keep all support coordinators informed. The rapid changes, without a thorough, statewide plan to purge prior information, contribute to the risk of missed information, resulting in inaccurate or incomplete information left on a website, brochure, form or other document.

Process Improvement

There is a gap in connecting families of transition age youth to the DD services system. The gap is two-fold, a knowledge gap between local school division personnel and CSB personnel, and lack of a formalized process to ensure families receive information about community-based services and supports. Some localities have excellent established practices and collaboration that could be replicated. Regulations covering Early Intervention outreach could be a model to establish a common practice of information sharing between education systems and CSBs.

Once people are connected to the DD services system, they may still have difficulty accessing information. The CSB intake process provides an opportunity to connect people to others with lived experience, but it does not appear to be fully utilized. When applying for Medicaid DD Waiver services, CSB intake forms include a check box asking if the family would like to speak with another family member. This assessment did not discover any formal procedure for assuring follow up when a family indicates yes on the form.

No formal process exists for assessing the level of satisfaction of people initially seeking information on applying for developmental disability services. For example, did they find the information they were looking for and did it meet their needs? There are no expectations or accountability for timely, accurate responses to families and individuals with disabilities when they make an inquiry, or formally request information from a local agency regarding services and supports available.

Evaluation efforts are further hindered by the lack of readily available data on the number of people who initially request information on how to access and apply for CSB/IDD services. There is no data available on the number of people who initially requested services but did not complete the application/eligibility process because they did not understand the instructions, could not navigate electronic forms, or requested services by using the wrong terminology and were turned away. It is unclear if the data is available at some CSBs, but CSB staff who participated in interviews were not aware of such contact data. DD Waiver Waiting List data

does not capture the number of people who applied for CSB services but were not found eligible. As required in the DOJ Settlement Agreement, data to improve the availability and accessibility of services, and to “enhance outreach, education and training,” must begin with accurate reporting of the number of people who seek such information and request assistance in the first place.

Quality, Accountability and Customer Focus

Cultural awareness and understanding and developing information with a user focus are important to people and were found lacking in many agencies. More than 50% of self-advocate responses related to useful information also identified a customer focus/supportive, respectful human contact as a key component of useful information. Conversely, accountability for inaccurate information, missing information and lack of respect for individual needs were identified by more than 50% of self-advocate respondents as negatively impacting the usefulness of information.

I/DD agencies in many states have implemented customer-focused quality improvement efforts to ensure their policies, implementation of services and review of service effectiveness are informed by customer experience. Virginia participates in one such effort called the National Core Indicators (NCI) project. NCI collects customer-informed quality data for people who already receive at least one service in addition to support coordination, but it does not provide the satisfaction levels of people who are waiting for services. In addition, the Centers for Medicare and Medicaid Services released a draft set of recommended quality measures for Medicaid-funded home and community-based services, which includes three areas relevant to information access. By prioritizing the recommendations found in this report, Virginia’s I/DD system will be well positioned to support future federal evaluation efforts.

Recommendations Related to Available, Accessible and Useful Information

1. The Virginia General Assembly should require DMAS, DBHDS and the Virginia Department of Social Services to collaboratively convene a workgroup with representatives from CSBs, LDSS, DARS, The Arc of Virginia, Virginia Board for People with Disabilities and additional stakeholders. The workgroup should (1) identify information needed across all service system partners, and (2) evaluate the existing data systems to determine if enhancing an existing data system and implementation of a business enterprise system can integrate all existing data systems so that immediate, accurate and reliable information is available for use by all CSBs and LDSS. This will minimize the reliance on individual and institutional knowledge of HCBS information and reduce the burden on families and people with disabilities to locate correct information regarding access to services.
2. As part of the renegotiation process of the performance contract, DBHDS and CSBs/BHA should include a requirement for CSBs/BHA to describe how they ensure 1) they meet requirements identified in Section 508 of the Rehabilitation Act of 1973 and W3C accessibility standards, and 2) access based on language and disability for all information

included on CSB/BHA websites. DBHDS should identify resources to monitor the performance contract for two years, and provide training opportunities to CSBs/BHA through subject matter experts with extensive knowledge in the area of recommended practices for meeting section 508 standards and assuring accessibility of electronic information as recommended by the W3C standards.

To identify current state-of-the-art practices, CSBs should review examples of highly accessible websites similar to the Ombuds Office of Developmental Disabilities in Washington State (<https://ddombuds.org/office-of-the-dd-ombuds-staff/>) and explore the benefits of available software programs which maximize accessibility of electronic materials such as [Recite Me](#) or [Internetrix](#).

3. Through its *Language and Disability Access Plan* (LDAP), DMAS should work collaboratively with DBHDS to develop simple, plain language graphic representations of the steps necessary to apply for Medicaid Eligibility and DD Waiver home and community-based services. The graphics should be distributed throughout the I/DD system in multiple languages that are most frequently spoken in each region of the Commonwealth. DMAS and DBHDS should commit to utilizing resources such as the U.S. Department of Health and Human Services Centers for Medicare & Medicaid Services *Toolkit for Making Written Material Clear and Effective*
4. DBHDS and CSBs/BHA should ensure a user-centric approach when developing new information for use by people with disabilities or their families by prioritizing the implementation of an Inclusive Design Process (<https://idrc.ocadu.ca/about/>) in their operating budgets. All new communications – electronic, printed documents, videos, audio files – should involve people with disabilities and their families to ensure it is accessible, easily understood and useful. DBHDS should consider if this fits within the role of the Individual and Family Supports Program (IFSP), including their regional Councils and other related activities, to develop a process for ensuring, at minimum, that people with lived experience who are the target audience have provided input and feedback on communications for families and self-advocates prior to distribution.

Recommendations Related to System Capabilities: Knowledge and Skills of Staff

5. DBHDS, with stakeholder input, should identify staffing within DBHDS responsible for proactively assuring people with I/DD, their families and appropriate CSB/BHA intake and support coordination staff have access to current, up-to-date and accurate simplified information on Medicaid HCBS program requirements including how the system functions, and how (in practical terms) to access the many and varied resources available.
6. DBHDS should expand on the existing regulations for support coordination training required within 30 days of employment and covered in the CSB Performance Contract

under Section 9(c)(5)-CSB Responsibilities/Scope of Services/ Case Management Services Training. Requirements for support coordinators should include annual training designed to promote understanding of the cultural and linguistic expectations targeted specifically to the cultural and ethnic population of the catchment area based on the number of people living there whose primary language is other than English and/or have Limited English Proficiency.

7. DBHDS should incentivize CSBs, possibly through a pilot project, to incorporate self-advocates in paid positions to bring perspective and experience to the training of support coordinators, including adding a self-advocate-led module in the required support coordinator training modules. The self-advocates, who represent diverse cultural, racial and ethnic backgrounds, can provide guidance through their lived experience on the education of individuals and families about services and supports and advise on the principles of person-centered planning and individualized supports.

Recommendations Related to Process Improvement

8. DBHDS and DMAS should establish a working group to identify effective methods for disseminating information such as ensuring (1) adults who seek information about I/DD services consistently receive referrals to the CSB/BHA, and (2) CSBs/BHA provide consistent information to people newly seeking services. The workgroup should also identify methods for ensuring the CSB and LDSS intake staff are aware of the Navigating the DD Waiver Manual and share it with families and people with I/DD at first contact. DBHDS should produce the manual in other languages and engage with applicable representatives from other cultures to ensure the translation is culturally and context sensitive.
9. During its annual review of the Navigating the DD Waiver Manual, DBHDS should expand and build on the existing flow chart and steps identified in the manual to further describe for families the documents needed and decision points made at each step of eligibility determination, so that statewide implementation of the intake process is consistent, and local agency intake staff have an information source to reference when introducing new referrals to the I/DD system.
10. DBHDS and CSBs/BHA should work together to further assess the need for including I/DD intake and eligibility process in the Community Services Performance Contract Scope of Work, with particular attention to length of time to complete the process, and the accuracy of information shared, similar to waiver performance measures. The process description could be developed with similar expectations as those found in the Early Intervention regulations regarding specific roles for referral sources, outreach to the community and timeliness of response.

11. DBHDS and CSBs/BHA should work collaboratively to determine the successfulness of the checkbox on intake forms which asks, *“Would you like to speak to a family member?”* They should determine if families and self-advocates who desire to speak with a family member can do so early in the process.
12. DBHDS should resume using a two-way feedback process with CSBs/BHA when implementing new procedures or requirements to ensure the new process is designed with input from CSB staff, families and people with lived experience, and includes a realistic implementation period. This approach, used in the past, would assist with assuring roll out of a new procedure considers existing resources, conflicting requirements or limitations, and the most efficient method for process re-design and development.
13. DBHDS should establish a method for determining if CSBs/BHA successfully met the family’s need for information/assistance (e.g., were needs met fully, partially, or not at all), during the intake and eligibility determination process. Refer to national plain language guidelines for assessing the effectiveness of written information at <https://www.plainlanguage.gov/guidelines/>. Similarly, DBHDS should require CSBs/BHA to seek feedback from families who call for initial intake support, regardless of the outcome of their application. For example, *Did we provide the information you were looking for? Did you understand the information? Does the information meet your need for the next steps?*
14. Virginia Department of Education (DOE), along with the local school divisions, should work with CSBs/BHA within the school division’s catchment area to designate a staff to act as a lead for school-to-adult life transition and work with the school division’s Transition Coordinator to ensure accurate and timely information is distributed to families. CSBs/BHA should utilize existing school-to-adult life transition resources such as PEATC's Transition University for CSB staff training and development.
15. The CSBs/BHA, through their member organization, Virginia Associations of Community Services Boards (VACSB), should consider operating a Community of Practice for School to Adult Transition, to foster learning and identify some of the exemplary practices taking place in several CSBs.

Recommendations for Quality, Accountability and Customer Focus

16. CSBs/BHA, through the Quality and Outcomes Committee in collaboration with DBHDS, should develop a framework for Quality Improvement based on nationally researched and established quality programs, similar to the Model For Improvement[®] demonstrated by the Institute for Healthcare Improvement (www.ihl.org) or the

Malcolm Baldrige National Quality Program (www.nist.gov/baldrige) to establish a formal framework through which a customer-focused, strategic and improvement-oriented system can emerge, and begin to expand beyond an exclusively compliance based quality model.

17. DBHDS and CSBs/BHA should utilize resources, such as The National Cultural and Linguistically Appropriate Standards (CLAS,) that describe a framework to deliver services that are culturally and linguistically appropriate, respectful, and responsive to cultural health benefits, preferences and communication needs for the population served. Standards can be employed by all members of the HCBS community. See [A Practical Guide to Implementing the National CLAS Standards December, 2018 CMS.gov](#) for guidance.

Background

The disability services system is complex, making it challenging for people with disabilities to navigate. In the Commonwealth of Virginia, as in most states across the United States, Medicaid home and community-based services and supports are administered through a complicated network of federal and state statutes, regulations, interagency contracts and agreements. Sub-regulatory documents developed by multiple state agencies provide interpretation and guidance on the implementation of procedures to meet the rules.

These complex rules governing the availability of services begin with the Social Security Act. The rules flow outward from the Centers for Medicare and Medicaid Services (CMS) to the Virginia Department of Medical Assistance Services (DMAS) and the Department of Behavioral Health and Developmental Services (DBHDS), through the local community agencies known as Community Services Boards/Behavioral Health Authority, referred to throughout this assessment as Community Services Boards (CSBs), and Local Departments of Social Services (LDSS). As illustrated in the graphic on the next page (Figure 1), the complex nature of the system is difficult to grasp. The system, when viewed as a whole, is a maze of compliance with rules governing administration of the services. The unintended result is a system that gives the impression of prioritizing compliance with rules above assuring a valuable and supportive experience for the people who depend on the system for their day-to-day support.

“...magic words are needed to open doors. If you don’t know the secret phrase the door won’t open, even if you are fully eligible.”

Parent of a 22-year-old son with autism

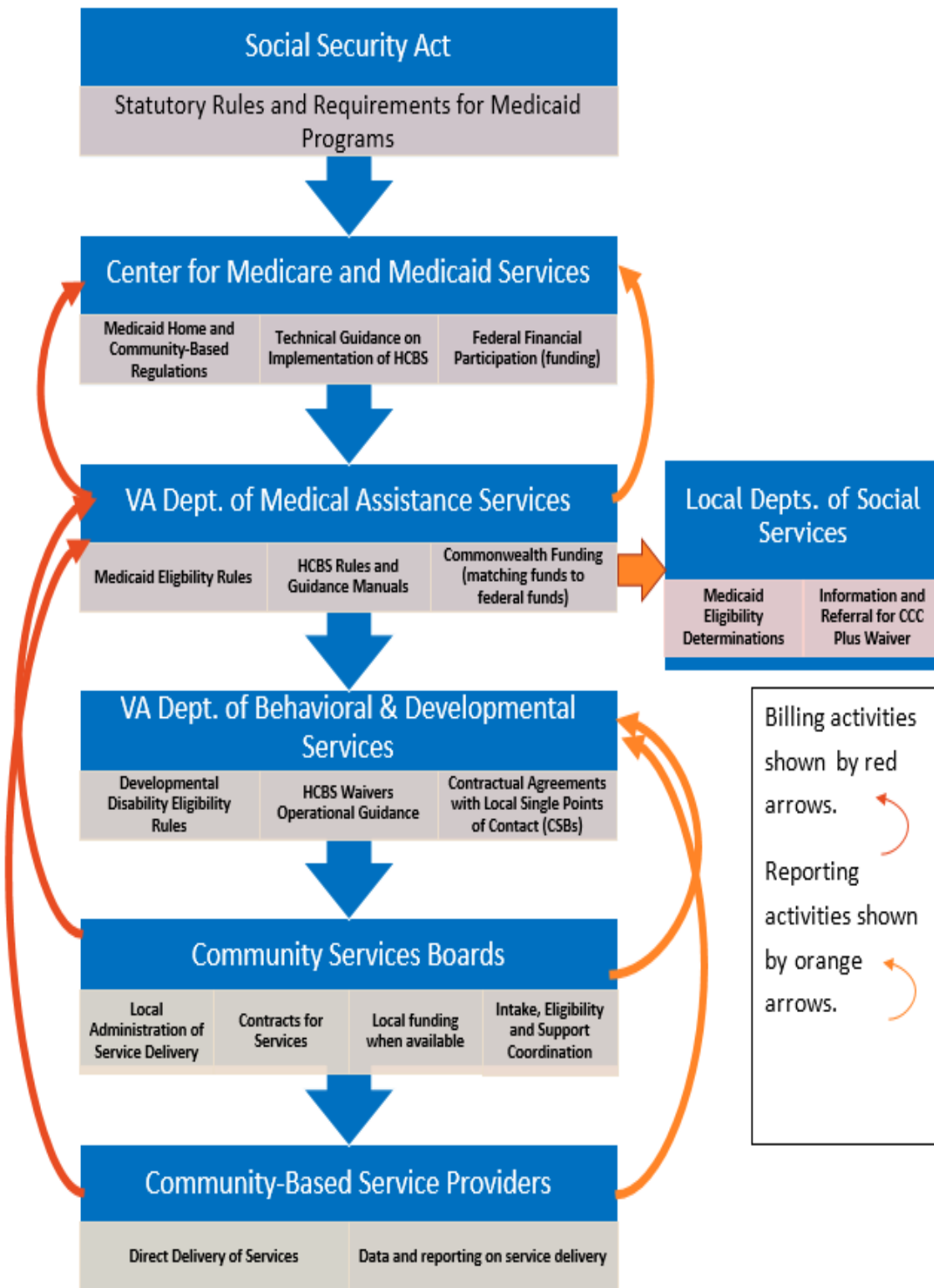
Many rules exist to support the availability, accessibility and usefulness of information. For example, Section 508 of the Rehabilitation Act of 1973 (29 U.S.C § 794 (d)) requires federal and state agencies to ensure information access is comparable for people with and without disabilities. In a 2012 Settlement Agreement with the U.S. Department of Justice (DOJ), Virginia committed to:

“...publish guidelines for families seeking intellectual and developmental disability services on how and where to apply for and obtain services. The guidelines will be updated annually and will be provided to appropriate agencies for use in directing individuals in the target population to the correct point of entry to access services.”

(United States of America v. Commonwealth of Virginia, 2012)

The Settlement Agreement also sets forth requirements for the collection of data to assess and improve quality, including reliable data to improve the availability and accessibility of services, to “*enhance outreach, education and training.*”

Figure 1. Rules, reporting, and funding regarding Medicaid home and community-based services (HCBS):



At the federal level, there may be increased focus on supporting information access in the near future. In a recently published proposed Access to Care Rule, CMS has signaled its potential interest in understanding states eligibility and enrollment procedures by asking for feedback on how to monitor eligibility determination denial rates and measure timely access to services. The CMS is also seeking information on how to determine the effectiveness of home and community-based outcome measures. Their draft recommended measures include three areas pertaining to the availability and usefulness of information which supports access to services:

- **Equity:** Addresses the extent to which support is equitably available to individuals seeking HCBS
- **Informed Decision Making:** Showing the level to which people are provided sufficient, understandable information to make decisions
- **Consumer Leadership and Development:** Evidence of meaningful consumer involvement, the level to which people have meaningful involvement in the design, implementation and evaluation of the HCBS System

State and local entities take different approaches to interpreting the various rules, which limits their effectiveness. For example, some state and local agencies view Section 508 of the Rehabilitation Act as a fundamental responsibility to ensure a valuable experience for people supported. Others view it as a compliance exercise to check off minimum standards from a list.

The Commonwealth of Virginia has an increasing imperative to provide consistent, timely, accurate and useful information for people with disabilities. The increased need is due to:

- The increasing needs of people seeking information
- The requirements established in the Department of Justice settlement agreement
- The Board's prioritization of the issue based on feedback from the disability community
- The convergence of numerous state and federal rules addressing increased access to home and community-based services

This assessment set out to answer questions in three categories:

1. Is information about home and community-based services available to individuals with I/DD and their family members? For example, does information exist in locations where people with disabilities and their family members frequently turn to for information?
2. Is information accessible? This question has three components:
 - Can information be readily located at the point in time when needed?
 - Is the information presented using plain easily understood language?
 - Is it available in multiple formats to accommodate varying linguistic and sensory communication needs? (e.g., accommodating Text-to-Speech software, enhanced or enlarged text, or offering accurate contextual translation from languages other than English)

3. Is the information useful? Does it answer pertinent questions and meet specific needs, does it provide tangible direction or assist with understanding what it takes to access home and community-based services?

The assessment research was guided by a workgroup and key partners. The research methods included:

Methods of Research	
Environmental Scan of Virginia and Other States (Appendix B)	
	<ul style="list-style-type: none"> • 36 state, local, and private agency staff • 27 website reviews • Document reviews
Focus Groups in Four Languages (Appendix C)	
	<ul style="list-style-type: none"> • 62 family members • 37 people with intellectual or developmental disabilities
Surveys in Two Languages (Appendix D)	
	<ul style="list-style-type: none"> • 107 family members • 26 people with intellectual or developmental disabilities

Key Findings: Available, Accessible and Useful Information

Available Information: A review of websites, documents and focus group feedback point to information that is highly technical, clinical and complex as a key barrier to being available, accessible and useful. At the earliest stage of searching for information, people do not know the questions to ask, are not familiar with technical and clinical language or jargon, and feel unprepared to use the correct terms when seeking information. The terminology used by agencies on website, in brochures, and in documents and forms is confusing and assumes extensive pre-existing knowledge of words and phrases such as “waiver,” “level of care,” “institutional placement” and “individualized supports.”

Families and self-advocates discussed their need for information at three stages:

- Seeking information about service access prior to any intake, or enrollment activity
- Seeking information about accessing new or different services after an eligibility determination resulted in enrollment on the Waiting List
- After enrollment in a DD Waiver

For these three distinct purposes, the availability of and access to information varies. Disability stakeholders have difficulty navigating websites to find information on community-based services and supports. When responding to the online survey, 56% of family respondents described state agency websites as difficult or very difficult to navigate, 51% identified local or county government agency websites as difficult or very difficult to navigate, while only 9.2% identified family advocacy organizations websites as difficult or very difficult to navigate. The

environmental scan activities discovered that nearly all CSB websites reviewed prominently displayed information on ‘same day access’ for Behavioral Health services on the website landing page, but many did not have similarly prominent information for intellectual or developmental disability services available on the same landing or homepage.

Michigan’s Approach

Michigan has taken steps towards implementing a business enterprise approach to its information technology platforms.

Michigan has established an “Open First” data policy to foster data sharing across the (full state) enterprise. The intent is to make a seamless experience for MI’s business partners who need access to information. The policy includes identifying master data across all state agencies; establishing a chief data steward in each state agency; and reducing the time and resources needed to share data by 50 percent. Work has begun to establish governance structures that will allow the state to use data and analytics to drive policy making and service delivery (Eggers and Hurst 2017)

Disability stakeholders also have difficulty understanding if the available information is relevant to them, thus spending significant time going from website to website in search of applicable information. Multiple websites exist that offer a searchable database of services available. Five such websites were reviewed:

- 1) mylifemycommunityvirginia.org
- 2) <https://easyaccess.virginia.gov/>
- 3) [211 Virginia.org](http://211.Virginia.org)
- 4) <https://commonhelp.virginia.gov/>
- 5) virgininavigator.org

The information on these sites frequently use similar generic terms (e.g., disability, rather than specific populations) making it hard for families and self-advocates to know if the information pertains to their situation. What might be accurate for the CCC Plus Waiver, for example, may not be accurate for the DD waivers in terms of eligibility criteria and services available. However, if a family calls their local department of social services (LDSS) to ask about “waiver services,” neither party may realize they are speaking of two different programs. Additionally, the websites lack detailed information on the steps necessary to access the services.

Relatedly, disability stakeholders also have difficulty understanding which websites to rely on for information. The websites not only duplicate information, but some information is not up to date, which results in information that appears contradictory or confusing at best. It is not easy to identify which websites are official Commonwealth of Virginia government websites, and which are offered by private agencies. Additional websites provide information on accessing services without a searchable database, further complicating the experience for stakeholders seeking help (see Appendix B).

A business enterprise system that integrates information across the various government-sponsored websites would improve the

ability of CSBs and LDSS staff to provide accurate and comprehensive information on available services. Business enterprise systems are designed to maximize the use of technology by integrating multiple state operated technology applications, formats and/or information protocols to minimize repetitive or manual tasks. For example, streamlining the identification of any Medicaid home and community-based services for which an individual is eligible. Services could include those offered by the CSB, its contractors, other service providers and LDSS. Another possible benefit, is maintaining and updating intake and eligibility protocols to multiple systems and websites anytime policy changes. See the sidebar example of another state, Michigan, which has benefited from the use of business enterprise systems. Technology-based business enterprise systems are commonly used in private enterprise agencies to increase the flow of accurate, up-to-date and relevant information to business partners and customers.

Designing and implementing a uniform, consistent and regularly maintained information access system would be a significant undertaking. A review of current data operating systems across various state agencies was out of the scope of this assessment. However, it is clear that a collaborative process of research and discovery to determine opportunities for enhancement and integration could modernize current systems. The benefits to local and state agencies, individuals and families, and provider networks would be systemic and result in improvements in access, efficiency and accuracy across the full disability system.

Additionally, disability stakeholders are not made aware of existing resources. For example, the *Navigating the DD Waivers Guidebook* available on the *My Life My Community* website is a useful document, written in plain language. The guidebook is written from a user's perspective, with step-by-step explanations of how to access home and community-based services. However, few families were aware of it, only one self-advocate had used the website, and none described or remembered receiving the guidebook from their CSB contact.

“...the person answering the phone just doesn't know or they send out information that is outdated.”

Family Focus Group Participant

Accessible Information: In order for information to be accessible, it should be provided in a manner that can be read, received, and understood by the audience it is intended for.

Mechanical or machine translation, which is computer software that automatically translates words from one language to another, does not provide accurate interpretation of most clinical and/or technical phrases. Machine translation also lacks context sensitivity, which often results in nonsensical sentences. Software such as Google Translate is easily available and free of charge, making it the most frequently used form of translation available on websites. Most families who speak languages other than English described their experience with machine translation as illogical or challenging to understand because the words, when taken out of context, can translate with very different meaning.

Many CSB websites do not provide translated information. One-third of CSBs in areas where 25% of homes speak languages other than English (*U.S. Census Data 2020*) do not have translation information readily available on their primary website. Common forms and

documents must be translated at the local agency level, inefficiently requiring each agency to pay for translation of the same or similar forms and resulting in inconsistent interpretation due to words with multiple meanings in languages other than English. While translation is helpful, best practices continue to be the presence of a human who knows the individual's language, the individual's culture, and the meaning of the words that require translation.

State agency (DMAS and DBHDS) websites provide 508 compliant adaptations and additionally meet ADA requirements, but many local agency websites do not. Section 11 Compliance with Laws in the FY 2022 and FY 2023 Community Services Performance Contract between DBHDS and CSBs addresses specific federal and state laws and regulations, but do not set out specific expectations for meeting or exceeding compliance with Section 508 as described above.

None of the websites reviewed met the highest standard for accessibility. Compliance with Section 508 of the Rehabilitation Act of 1973 tends to focus only on sensory disability standards such as vision and hearing access. The Cognitive and Learning Disabilities Accessibility (COGA) Task Force recommended Cognitive Disability Accessibility Standards for assuring access to people with intellectual/cognitive disability. These are considered the "highest" standard to meet as they are highly customized to the individual's needs. Some examples include websites that do not time out, linear navigation systems, and "breadcrumbs" to where you've been/where you are. When the primary base of users of the information are people with intellectual or cognitive disabilities, it is important from a customer service perspective to strive to meet the Cognitive and Learning Disabilities recommendations and not settle for compliance with 508 standards.

Government agency websites are largely written for professionals in the field, yet there is not a co-existing website or web page, other than *My Life My Community*, which demonstrates the highly recommended user-centric design or application of universal design standards. The development of a user focus is largely defined as a "deep understanding of your users, what they need, what they value, their abilities" and takes into account why the user is interacting with your organization. The General Services Administration (GSA) for the United States operates a website called Digital.gov (<https://digital.gov>) with a mission of helping government agencies make digital information effective and accessible. The GSA makes clear the importance of customer experience (CX) and user-centric design: "Government is often a sole-source service provider, making CX even more important in the public sector than in other organizations."

An additional promising practices related to user-centric design is the collaboration of self-advocacy organizations and local state agencies on trainings and materials used to inform self-advocates of policy changes, new programs and other critical information. Green Mountain Self-Advocates, located in Vermont, operates the national Self-Advocacy Resource and Technical Assistance Center (SARTAC). SARTAC provides resources and webinars pertaining to the use, differences and importance of Plain Language and Easy Read Text. The resources prove invaluable for self-advocates and organizations responsible for distributing information. DMAS, DBHDS, its self-advocacy community and CSBs can access free available resources through their

website: [Home - SARTAC \(selfadvocacyinfo.org\)](http://Home-SARTAC(selfadvocacyinfo.org)). One example of a useful resources is the webinar, Overview of Accessible Formats, which provides innovative ideas on inclusive design in the editing process.

Plans exist to improve accessible information. DMAS recently issued its Language and Disability Access Plan, describing its current status and future goals for assuring access to information for people with limited English proficiency and individuals with disability. One of the five strategic initiatives describes stakeholder involvement to enhance language and disability access to Medicaid programs.

Useful Information: Information located by families does not provide explanations of the steps needed to access services, and is more likely to describe rules, regulations, or individual rights. Families identified practical, tangible, responsive information that results in action and is delivered by another human in the family’s preferred language as the most useful. Self-advocates rely on information that comes from a trusted, credible source and are more likely to call to talk with another person than rely on written information.

“Our neighbor told us about annual seminars at our local Fairfax County Government Center and Integrated Living Opportunities, which provides much needed information.”

Participant in Korean Family Focus Group

Government websites, which families frequently seek out, do not provide useful information. In a survey, 75% of families reported first seeking information from state government websites, 82% reported utilizing local government websites, 71% reported seeking information from family/advocacy organizations and 73% of families responding to the survey reported relying on other families for information. However, only 23% of the respondents identified state government agency websites as either useful or very useful and 27% identified local government website information either useful or very useful. Meanwhile, 66% described information from family advocacy organizations as useful or very useful and 73% described information from other families as useful or very useful, the highest percentage identified in this question. These results coincide with feedback from families during the focus groups.

Disparities in internet access limit the usefulness of electronic information. In areas with limited internet access, reliance on other people, either professionals or other family members, to deliver accurate and timely information is crucial. Similarly, areas with high populations of aging caregivers should provide information through human contact rather than relying solely on electronic distribution methods. Many people with I/DD live with aging parents and it is not uncommon for people to be supported by their grandparents. This population is much less likely to have technology skills or the savvy to know how to use multiple searches, or persistently seek difficult-to-find information and understand its meaning.

Recommendations Related to Available, Accessible and Useful Information

1. The Virginia General Assembly should require DMAS, DBHDS and the Virginia Department of Social Services to collaboratively convene a workgroup with representatives from CSBs, LDSS, DARS, The Arc of Virginia, Virginia Board for People with Disabilities and additional stakeholders. The workgroup should (1) identify information needed across all service system partners, and (2) evaluate the existing data systems to determine if enhancing an existing data system and implementation of a business enterprise system can integrate all existing data systems so that immediate, accurate and reliable information is available for use by all CSBs and LDSS. This will minimize the reliance on individual and institutional knowledge of HCBS information and reduce the burden on families and people with disabilities to locate correct information regarding access to services.
2. As part of the renegotiation process of the performance contract, DBHDS and CSBs/BHA should include a requirement for CSBs/BHA to describe how they ensure 1) they meet requirements identified in Section 508 of the Rehabilitation Act of 1973 and W3C accessibility standards, and 2) access based on language and disability for all information included on CSB/BHA websites. DBHDS should identify resources to monitor the performance contract for two years, and provide training opportunities to CSBs/BHA through subject matter experts with extensive knowledge in the area of recommended practices for meeting section 508 standards and assuring accessibility of electronic information as recommended by the W3C standards.

To identify current state-of-the-art practices, CSBs should review examples of highly accessible websites similar to the Ombuds Office of Developmental Disabilities in Washington State (<https://ddombuds.org/office-of-the-dd-ombuds-staff/>) and explore the benefits of available software programs which maximize accessibility of electronic materials such as [Recite Me](#) or [Internetix](#).

3. Through its *Language and Disability Access Plan* (LDAP), DMAS should work collaboratively with DBHDS to develop simple, plain language graphic representations of the steps necessary to apply for Medicaid Eligibility and DD Waiver home and community-based services. The graphics should be distributed throughout the I/DD system in multiple languages that are most frequently spoken in each region of the Commonwealth. DMAS and DBHDS should commit to utilizing resources such as the U.S. Department of Health and Human Services Centers for Medicare & Medicaid Services' [Toolkit for Making Written Material Clear and Effective](#).
4. DBHDS and CSBs/BHA should ensure a user-centric approach when developing new information for use by people with disabilities or their families by prioritizing the implementation of an Inclusive Design Process (<https://idrc.ocadu.ca/about/>) in their

operating budgets. All new communications – electronic, printed documents, videos, audio files – should involve people with disabilities and their families to ensure it is accessible, easily understood and useful. DBHDS should consider if this fits within the role of the Individual and Family Supports Program (IFSP), including their regional Councils and other related activities, to develop a process for ensuring, at minimum, that people with lived experience who are the target audience have provided input and feedback on communications for families and self-advocates prior to distribution.

Key Findings: System Capabilities - Staff Knowledge and Skills

There are some state efforts to ensure that informational materials are up to date, but there are opportunities to further improve and streamline these efforts. The highly complex and frequently changing nature of Medicaid HCBS information requires constant attention from the agencies responsible for assisting families to navigate the initial application process. DBHDS has implemented numerous system improvements over the past several years, some in response to the DOJ Settlement Agreement and many at the Department’s own initiative. Each office of the Department is responsible for ensuring information and policy changes are clearly communicated and disseminated, including requesting updates to the agency’s websites. The pace and volume of changes occurring makes it difficult to track all relevant communications. It is unclear if there are dedicated staff across the agency responsible for coordinating system-wide information updates in a comprehensive manner.

Staffing challenges at CSBs hinder their ability to provide up-to-date information. The separation rate among support coordination staff in 2018 averaged 28.2% across Virginia, and ranged from 0% to 75% (*Dinora and Bogenschutz p. 15*). These high turnover rates result in staff who are less knowledgeable about the complex Medicaid rules. When these staff provide inaccurate information, it is left to the families and self-advocates to correct them.

“The case managers in our county are drowning in their caseloads. They really want to help, but they just can’t do it all. It would be so helpful to have someone who can just focus on supporting families.”

CSB Representative

The knowledge and skill of agency staff was the most frequently identified barrier by families to accessing information. Families report feeling disrespected when pointing out contradictory information and feel particularly vulnerable when inquiring about inconsistent information between agencies. Several families reported staff from a local agency becoming dismissive or argumentative when the family reported that another agency had given them contradictory information. Families and self-advocates who do not know the information is incorrect may be dissuaded from applying for Medicaid services.

“I was told that since my son has private health insurance he would not be eligible for Medicaid. I did not know what Medicaid Waiver was, so I didn’t know to ask more questions. It wasn’t until I found out from other families that I realized Medicaid Waiver is different from Medicaid for Health Insurance.”

Focus Group, Mother of a 3-year-old Son

The inaccurate and contradictory information increases the volume of phone calls to agencies. Families have to make multiple calls to confirm information. Self-advocates and family members identify this as a contributor to wasted time and resources, and frustration leading to giving up the search. Accurate information is crucial to accessing services in a timely manner.

Technology solutions exist that the Commonwealth could leverage to improve information availability and accessibility, as described above. Access to a statewide business enterprise system identified in Recommendation #1 would make it unnecessary for support coordination and intake staff to memorize the details and variations of criteria associated with multiple HCBS waiver options available.

There are also opportunities to coordinate across CSBs. For example, all CSBs could benefit from Fairfax County CSB’s infographics and easy to read checklists. Rapidly changing information, procedures, and documents require each of the 40+ local agencies to update forms, manuals, and instructions, often without enough time to keep all support coordinators informed. The rapid changes, without a thorough, statewide plan to purge prior information, contributes to the risk of inaccurate or incomplete information left on a website, a brochure, a form, or other document.

Recommendations Related to System Capabilities: Knowledge and Skills of Staff

5. DBHDS, with stakeholder input, should identify staffing within DBHDS responsible for proactively assuring people with I/DD, their families and appropriate CSB/BHA intake and support coordination staff have access to current, up-to-date and accurate simplified information on Medicaid HCBS program requirements including how the system functions, and how (in practical terms) to access the many and varied resources available.
6. DBHDS should expand on the existing regulations for support coordination training required within 30 days of employment and covered in the CSB Performance Contract under Section 9(c)(5)-CSB Responsibilities/Scope of Services/ Case Management Services Training. Requirements for support coordinators should include annual training designed to promote understanding of the cultural and linguistic expectations targeted specifically to the cultural and ethnic population of the catchment area based on the number of people living there whose primary language is other than English and/or have Limited English Proficiency.
7. DBHDS should incentivize Community Services Boards, possibly through a pilot project, to incorporate self-advocates in paid positions to bring perspective and experience to

the training of support coordinators, including adding a self-advocate-led module in the required support coordinator training modules. The self-advocates, who represent diverse cultural, racial and ethnic backgrounds, can provide guidance through their lived experience on the education of individuals and families about services and supports and advise on the principles of person-centered planning and individualized supports.

Key Findings: Process Improvement

People with disabilities have difficulty connecting to the disability services system, especially after they exit the education system. Families with a newly diagnosed infant or toddler with a disability report that health care professionals provide crucial links to both family advocacy agencies and to local Early Intervention provider agencies. Families with school-age children rely on school systems or other families to provide information about supports and services available. For individuals with I/DD who have exited the school system, the source of information regarding access to services is the CSB. DBHDS identifies CSBs as the single point of entry for I/DD services. For families not directly connected to the CSB prior to their son or daughter finishing his or her formal education, it is “luck, just pure luck” that they will find the connection according to one family member.

There are opportunities to improve the process for connecting people with disabilities to CSBs. There is an outreach process for Early Intervention services called Child Find (12VAC35 – 225-50). There is no corollary process for connecting families of transition age youth to the DD services system. Additionally, there is often a knowledge gap between local school division personnel and CSB personnel. Some localities have excellent established practices and collaboration that could be replicated. A proactive approach toward establishing a seamless handoff between the education system and adult services would mitigate the “cliff,” as it is described by families of recent high school graduates.

Examples of related best practices include the following:

- Fairfax County CSB has established a school-to-adult life transition team which works closely with the local schools to provide consistent information to students, families and school representatives regarding ID/DD services and resources.
- Fairfax County CSB utilizes an array of internal Job Aides for information and referral that are described for staff in a clearly defined process. The Support Coordinators are trained on all processes upon hire, retrained annually and retrained any time there is a process change or release of new information. To assist with staying abreast of the constant changes, Fairfax utilizes weekly lunch & learns and monthly meetings to share information.
- Chesterfield County CSB in collaboration with the local schools, developed videos on available services and resources so that families and teachers can better access the information.

- Mount Rogers CSB is intentional about support coordinators working closely with their local schools to provide information. The CSB holds public awareness events and utilizes materials provided by DBHDS, such as the “simplified” waiver guide that explains how eligibility is determined, to effectively distribute information.

Once people are connected to the DD services system, they may still have difficulty accessing information. Self-advocates sometimes have three or more entities that serve a case management function. For example, someone might receive support coordination from a CSB, have a vocational rehabilitation counselor who oversees DARS employment services, and have a Medicaid care coordinator. Nonetheless, they may still have trouble finding the answers to questions or getting approvals for necessary services.

The CSB intake process provides an opportunity to connect people to others with lived experience, but it does not appear to be fully utilized. CSB intake forms include a check box asking if the family would like to speak with another family member. However, this assessment did not discover any formal procedure for assuring follow up when a family indicates yes on the form. This is a promising opportunity to connect families, which was expressed by the majority of families as a priority and preferred method of getting information.

“Our health department told me the Waiver is only for people in nursing homes, not for school-age students.”

Focus Group Participant

Application materials for Medicaid waivers can be confusing. For example, the Level of Care documents for the Commonwealth Coordinated Care Plus (CCC Plus) Waiver ask the applicant if they expect their family member will need to be placed in a

nursing facility within the next 30 days, even if their family member is a child. Similarly, the Level of Care for DD waiver services requires families to agree their son or daughter needs “an institutional level of care.” Families are confused and offended by this question. Regardless of the system’s need to confirm this level of care, it is a confusing process to ask families to sign a form choosing community-based services while at the same time asking them to sign another form agreeing their son or daughter needs an institutional level of care.

There are opportunities to better communicate the Level of Care requirements to family members. While this is a federal requirement in the 1915(c) HCBS Waiver, it is inconsistent with federal principles of person-centered, home and community-based systems of support. It is also incongruous that it is a key step in a process under a Department of Justice settlement agreement to promote community living outside of institutions. Virginia could benefit from consultation with National Association of State Directors of Developmental Disabilities Services (NASDDDS) on practices utilized by neighboring states such as Ohio, Pennsylvania and Maryland each of which requires a clinician to document the need for an institutional level of care, but does not require families to explicitly state the need. Many states, in the Freedom of Choice documentation, emphasize the choice of services in home and community-based settings, with underemphasized focus on the words ‘institutional care.’ Requesting an institutional level of care is also a strong example of translation confusion, with families who are not primary English

speakers reporting confusion and alarm over requirements to declare they are seeking to place their family member in an institution. For people with distrust of government agencies, this requirement presents a significant barrier to accessing services.

There are no clear expectations for CSBs to provide information on disability services to interested families. Section 9.C, “CSB Responsibilities/Scope of Services,” within the CSB Performance Contract addresses same day access for a mental health or substance use disorder assessment and primary care screening and monitoring for children with serious emotional disturbance. However, it does not describe similar expectations for timely, accurate responses to families or individuals with I/DD who make an initial inquiry or request services from the CSB.

Formal evaluation of information access is limited. CSBs are required to ask anyone receiving HCBS Waiver services if they are satisfied with services on a quarterly basis. However, none of the CSBs that were interviewed collect feedback on the experience of people who applied for services, regardless of whether their application was successful. Additionally, DMAS and DBHDS do not recommend that CSBs collect this information.

Evaluation efforts are further hindered by the lack of readily available data on the number of people who initially request information on how to access and apply for CSB/IDD services. There is no data available on the number of people who initially requested services but did not complete the application/eligibility process because they did not understand the instructions, could not navigate electronic forms, or requested services by using the wrong terminology and were turned away. It is unclear if the data is available at some CSBs, but CSB staff who participated in interviews were not aware of such contact data. DD Waiver Waiting List data does not capture the number of people who applied for CSB services but were not found eligible. When turned away, people were often not connected to the “appropriate” agency. As required in the DOJ Settlement Agreement, data to improve the availability and accessibility of services, and to “enhance outreach, education and training,” must begin with accurate reporting of the number of people who seek such information and request assistance in the first place.

Recommendations Related to Process Improvement

8. DBHDS and DMAS should establish a working group to identify effective methods for disseminating information such as assuring (1) adults who seek information about I/DD services consistently receive referrals to the CSB/BHA, and (2) CSBs/BHA provide consistent information to people newly seeking services. The workgroup should also identify methods for assuring the CSB and LDSS intake staff are aware of the Navigating the DD Waiver Manual and share it with families and people with I/DD at first contact. DBHDS should produce the manual in other languages and engage with applicable representatives from other cultures to ensure the translation is culturally and context sensitive.

9. DBHDS during its annual review of the Navigating the DD Waiver Manual, should expand and build on the existing flow chart and steps identified in the manual to further describe for families the documents needed and decision points made at each step of eligibility determination, so that statewide implementation of the intake process is consistent, and local agency intake staff have an information source to reference when introducing new referrals to the I/DD system.
10. DBHDS and CSBs/BHA should work together to further assess the need for including I/DD intake and eligibility process in the Community Services Performance Contract Scope of Work, with particular attention to length of time to complete the process, and the accuracy of information shared, similar to waiver performance measures. The process description could be developed with similar expectations as those found in the Early Intervention regulations regarding specific roles for referral sources, outreach to the community and timeliness of response.
11. DBHDS and CSBs/BHA should work collaboratively to determine the successfulness of the checkbox on intake forms which asks, *“Would you like to speak to a family member?”*. They should determine if families and self-advocates who desire to speak with a family member can do so early in the process.
12. DBHDS should resume using a two-way feedback process with CSBs/BHA when implementing new procedures or requirements to ensure the new process is designed with input from CSB staff, families and people with lived experience, and includes a realistic implementation period. This approach, used in the past, would assist with assuring roll out of a new procedure considers existing resources, conflicting requirements or limitations, and the most efficient method for process re-design and development.
13. DBHDS should establish a method for determining if CSBs successfully met the family’s need for information/assistance e.g. were needs met fully, partially, or not at all, during the intake and eligibility determination process. Refer to national plain language guidelines for assessing the effectiveness of written information, found at <https://www.plainlanguage.gov/guidelines/>. Similarly, DBHDS should require CSBs to seek feedback from families who call for initial intake support, regardless of the outcome of their application. For example: Did we provide the information you were looking for? Did you understand the information? Does the information meet your need for the next steps?
14. Virginia Department of Education, along with the local school divisions, should work with CSBs/BHA within the school division’s catchment area to designate a staff to act as a lead for school-to-adult life transition and work with the school division’s Transition Coordinator to ensure accurate and timely information is distributed to families.

CSBs/BHA should utilize existing school-to-adult life transition resources such as PEATC's Transition University for CSB staff training and development.

15. The CSBs/BHA, through their member organization VACSB, should consider operating a Community of Practice for School to Adult Transition, to foster learning and identify some of the exemplary practices taking place in several CSBs.

"I won't take no for an answer... but most families do not have the energy to keep at it so hard."

Mother of a daughter with Down syndrome

Key Findings: Quality, Accountability and Customer Focus

Stakeholders identified lack of accountability of agency staff as a primary concern. During focus

groups, families described disappointment over the fragmented service system, resulting in a lack of accountability for fixing inaccurate information. Families reported that when confronting an agency with misinformation, the agency often blamed another component of the system, or indicated they are not the original source of creating the information but are simply the messenger. Similarly, over 50% of self-advocate respondents reported no apparent accountability for inaccurate information, missing information, and lack of respect for individual needs as factors negatively impacting the usefulness of information.

Customer focus approaches are present in some CSBs and LDSS, but not all. More than 50% of self-advocate responses related to useful information identified a customer-focused, supportive and respectful human contact as a key component of useful information. Families consistently reported they must know exactly what to ask, specific key terms, and the "correct" answers to questions to accurately complete forms and apply for services. For example, applicants for services frequently do not understand questions about institutional level of care needs but reported not getting support or explanations from most local departments of social service intake staff. When asking for support or services for their son or daughter, families feel they are treated disrespectfully, as if they are "looking for a handout." When CSB support coordinators leave, families are often not informed and a vital connection is broken.

Virginia should expand its quality assurance efforts so that all people who seek information have the opportunity to provide feedback on their experience. Many state I/DD agencies have implemented customer-focused quality improvement efforts to ensure their system policies, implementation of services, and review of service effectiveness are informed by customer experience. For example, Virginia and 46 other states participate in the National Core Indicators (NCI) program, which seeks feedback from individuals who receive support coordination and one additional service, and their family members. However, NCI does not include people who are in initial stages of accessing services or are not yet receiving Medicaid Waiver services. Therefore, NCI survey results cannot be broadly applied to people not enrolled in services or on the waiting list. States have a variety of methods for implementing improvement based on the feedback of people receiving services, and several states also include feedback from people who

are waiting for services. For example, Massachusetts and Missouri have formal quality improvement systems which include assuring timely access to information, prior to service enrollment. In addition, Empowerline, the Atlanta Region's Aging and Disability Resource Connection, utilizes satisfaction surveys for all calls requesting information. The survey seeks to understand the caller's experience with the agency, if their question was resolved, and if the caller is satisfied with the level of knowledge of the person who answered their call.

Recommendations for Quality, Accountability and Customer Focus

16. CSBs, through the Quality and Outcomes Committee in collaboration with DBHDS, should develop a framework for quality improvement based on nationally researched and established quality programs, similar to the Model For Improvement[®] demonstrated by the Institute for Healthcare Improvement ([IHI How to Improve](#)) or the Malcolm Baldrige National Quality Program (www.nist.gov/baldrige) to establish a formal framework method through which a customer-focused, strategic and improvement-oriented system can emerge, and begin to expand beyond a predominantly compliance based quality model.
17. DBHDS and CSBs should utilize resources, such as The National CLAS Standards that describe a framework to deliver services, that are culturally and linguistically appropriate, respectful, and responsive to cultural health benefits, preferences and communication needs for the population served. Standards can be employed by all members of the HCBS community. See [A Practical Guide to Implementing the National CLAS Standards December, 2018 CMS.gov](#) for guidance.

Appendix A: Acknowledgements

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Appendix B: Environmental Scan

The environmental scan activities included:

- Assessments of websites from state and local government agencies and private service and advocacy agencies
- Review of federal and state statute and regulations, state and local government agency policies, guidance documents and manuals, and legal documents including the Dept. of Justice and Commonwealth of Virginia Settlement Agreement and formal contracts held between the Virginia DBHDS and Local Community Services Boards (CSBs)
- Interviews with employees of state and local government agencies and private service and advocacy agencies
- Interviews and discussions with nationally recognized subject matter experts

The purpose of the scan was to determine the degree of information availability, accessibility, and usefulness pertaining to accessing community services by people with Intellectual Disabilities and/or Developmental Disabilities (I/DD).

Interviews

The scan included interviews with current employees from the Virginia Department of Medical Assistance Services (DMAS), the Virginia Department of Behavioral Health and Developmental Services (DBHDS), the Department for Aging and Rehabilitative Services (DARS), No Wrong Door program, leadership team members from four CSBs, and the Virginia Association of Community Services Boards (VACSB). Websites of each of these agencies were assessed including www.mylifemycommunityvirginia.org and <http://easyaccess.virginia.gov/> along with websites of private service providers and Information and Referral services.

	State Agencies	CSBs	Private Agencies	External Agencies
Websites Reviewed	4	15	4	4
Interviews with Agency representatives	6	5	5	5
People Interviewed	12	5	12	7

Website Reviews

The website review consisted of related stakeholders in Virginia including 15 CSBs, DBHDS, DMAS, DARS and the No Wrong Door program. The review also included websites of private organizations and related stakeholders outside the Commonwealth that subject matter experts identified as accessible and user friendly. Social media pages, routinely offered orientation sessions, training modules, on-line brochures and videos were included.

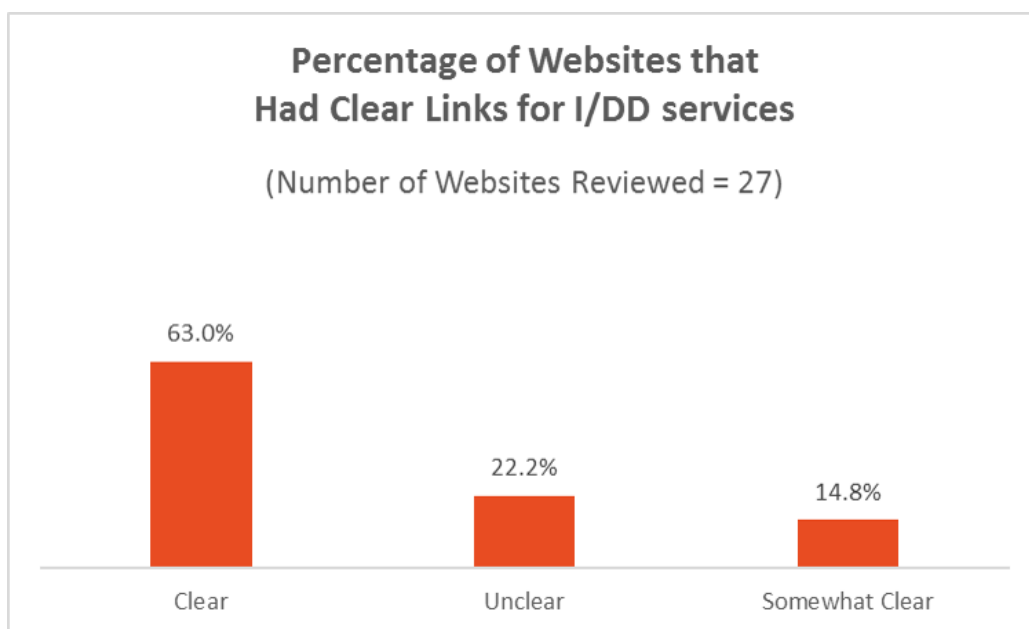
The environmental scan reviewed the following factors:

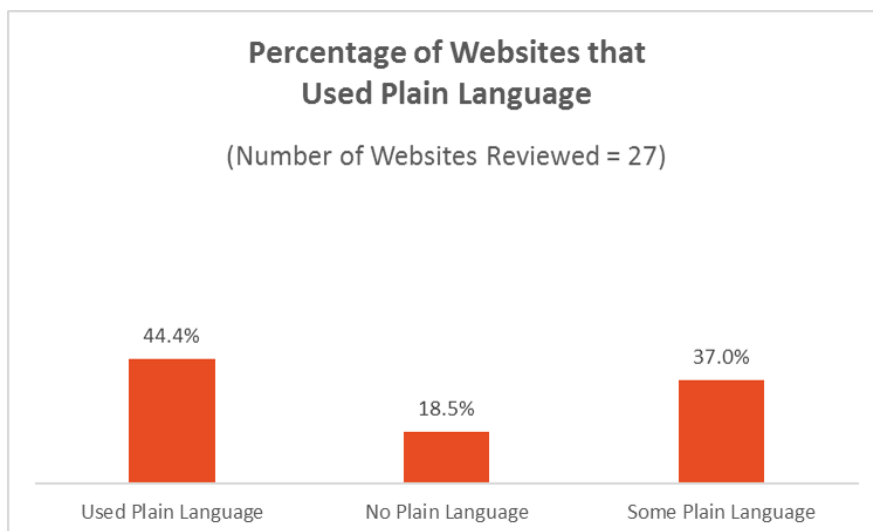
- Availability and ease of locating information upon landing on a website's main page
- Accessibility regarding 508 compliance e.g., alternative print, accessibility menus, text to speech compatibility, etc.
- Availability of information in alternative languages (machine translation as well as headers with alternative language messages on how to access more information)
- The extent of cultural and linguistic diversity of the information
- Plain language and usefulness of information

All factors were identified as present, not present, or somewhat present, with definitions for each level. The environmental scan was guided by an End User Workgroup formed at the start of the Assessment Project, and by subject matter experts and guidelines from the W3C Web Accessibility Initiative (WAI).

Stories shared by individuals and families during the focus group activities (see Appendix B) provided a better understanding of firsthand experiences and expectations of end users when accessing websites and other forms of information. This in turn informed some of the environmental scan follow up interviews with state and local government agency employees.

Some of the findings are depicted in the charts below. Nearly two-thirds of main webpages had a clear link to I/DD services. Fewer than half of websites used plain language.





During the environmental scan, seven separate websites describing eligibility procedures for accessing services were located.

- DBHDS’s Developmental Disabilities Waiver website <https://www.mylifemycommunityvirginia.org/>
- DARS No Wrong Door website <https://easyaccess.virginia.gov/>;
- Virginia 211 Human Service Access website <https://211virginia.org/consite/index.php>
- Medicaid Eligibility website developed by Maximus: <https://coverva.org/en>
- Department of Social Services website for Medicaid Applications <https://commonhelp.virginia.gov/>
- Department of Medical Assistance Services website <https://www.dmas.virginia.gov/>
- A non-profit Guide for People with Disabilities, People who are Aging, and Veterans <https://virgininavigator.org>.

Document Review

Related policies, procedures, contracts and regulations were reviewed to gain a better understanding of rules, requirements and expectations for information development, maintenance and distribution. The review targeted identification of indicators of organizational roles, responsibilities, and authority for information availability, accuracy and use. Interviews were conducted with state and local governments and private organizations to determine the strategies used to carry out obligations identified in policy or rule. These interviews focused on practical applications of the rules and regulations and how agencies determine effectiveness of their actions. Questions included, who is responsible, how information is made available in multiple languages, factors contributing to individual and family perceptions of information availability, how agencies gather user input to information distribution materials and methods, the impact of technology, and how the state prioritizes the availability and accessibility of information. Interviews included discussion of barriers to information availability, examples of steps taken to improve information availability, usefulness and opportunities for improvement currently being pursued or planned for the future.

Appendix C: Focus Groups

Focus groups were conducted to collect qualitative and quantitative information to assess how and where individuals with disabilities and families access information and to determine if the information is perceived as useful and meets their needs. Focus groups were conducted in all five (5) regions of the state and gathered firsthand information on the experiences of individuals and families seeking information on community services and support.

Focus Group Participants

The Arc of Virginia, The Center for Family Involvement at Virginia Commonwealth University (VCU) and EnDependence Center of Northern Virginia (ECNV) assisted with the recruitment of participants for the focus groups. Focus groups for individuals with disabilities were co-facilitated by self-advocates from the ALLY Alliance. The Arc of Virginia assisted with training and support for self-advocates and co-facilitators for the focus groups, explaining the purpose of the focus group and confirming participation across the five regions.

Additional support was provided for focus groups in other languages. The Center for Family Involvement assisted with coordination and translation services for two (2) focus groups held for people using Spanish as their primary language and one (1) for a focus group in Arabic. ECVN provided translation of the PowerPoint into Korean and Spanish and facilitated four of the focus groups in the group's primary language, one (1) in Korean and three (3) in Spanish. ECVN acknowledged the importance of cultural values and connected individually with each family to share the purpose of the focus group, build trust and recruit participants. ECVN provided transcripts of translated information gathered in the focus groups.

A total of seventeen (17) focus groups were held. Twelve (12) Focus groups were with a total of 62 Family Members. They included:

- Five (5) held in English
- Five (5) held in Spanish
- One (1) held in Arabic
- One (1) held in Korean

Another five (5) focus groups were held with a total of 37 self-advocates. These self-advocate focus groups were in English. Race and ethnicity data for the focus group participants is shown below.

Family Groups by Race/ Ethnicity	Number of Family Groups by Race/Ethnicity	Self-Advocate Groups by Race/ Ethnicity	Self-Advocate Groups by Race/Ethnicity
Black or African American	4	Black or African American	9
White/Caucasian	25	White/Caucasian	26

Family Groups by Race/ Ethnicity	Number of Family Groups by Race/Ethnicity	Self-Advocate Groups by Race/ Ethnicity	Self-Advocate Groups by Race/Ethnicity
Hispanic or Latino	23	Hispanic or Latino	0
Asian	5	Asian	1
Race Unknown	5	Race Unknown	1
Total Family Participants	62	Total Self-Advocate Participants	37

Focus Group Questions

The focus group questions were developed with support from the Human Services Research Institute (HSRI) and Virginia Commonwealth University (VCU) Partnership for People with Disabilities. The questions covered specific methods people used to find information, ease of access, topic of information sought, the perceived usefulness of the information, and suggestions for improvement. Each question was shared by the focus group facilitator and shown in a PowerPoint slide deck. Written text was accompanied by icons and plain language.

An explanation in plain language of availability, accessibility, and usefulness of information regarding I/DD services and resources was provided to the participants at the beginning of each focus group. The focus group questions are listed below.

Questions Asked of Self-Advocates:

- Where do people find out about available help and support?
- Where do people find out about doctors, medical support, or therapies?
- Where do people find help to pay bills or help with food assistance?
- If you receive Medicaid Waiver services and you need more help or support such as help to find a job or more help in your home, who do you ask or where would you look?
- Is there anyone that has been helpful in assisting you to find information?
- If someone helped you, what was it they did that made it helpful?
- Have you looked for information on a website?
- What made it easy or hard to find the information?
- If you found information, was it explained in a way that you could understand?
- Where there words on the website that you did not know or understand?
- Did the website tell you who to call for more information or for someone to help you?
- Are there other ways you find out information (i.e., brochures, support or self-advocacy groups, organizations, Facebook and other social media)?
- Think about a time you did find information and it helped you get the help and support you needed; how did it change your life?
- What is one thing that could be done to improve information being available and accessible to people with disabilities and other people that need the information?

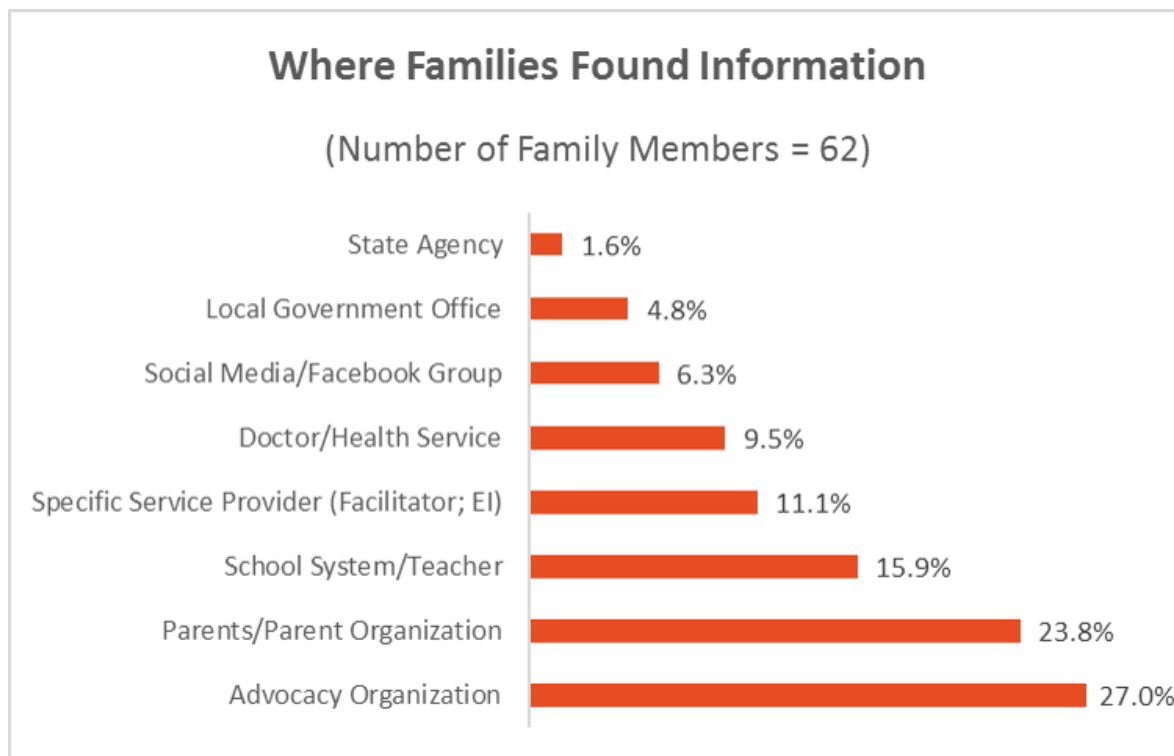
- (Poll question) Where people have looked for information?
- (Poll question) How long it took to find information?
- (Poll question) Factors that made the information useful?

Questions Asked of Families:

- Where have you looked for information for your son or daughter?
- Who informed you information was available and where to look?
- If your son or daughter receives the Medicaid Waiver and needs additional services, do you know who to ask or what to do?
- Have you looked on a website or other social media platforms?
- How easy was it to find and access the information you were looking for?
- If you found information, what factors made it most helpful or useful?
- What impact did either finding or not finding information have on you, your son or daughter?
- If there is one thing that could be done to improve access to information for people with I/DD in Virginia, what would it be?

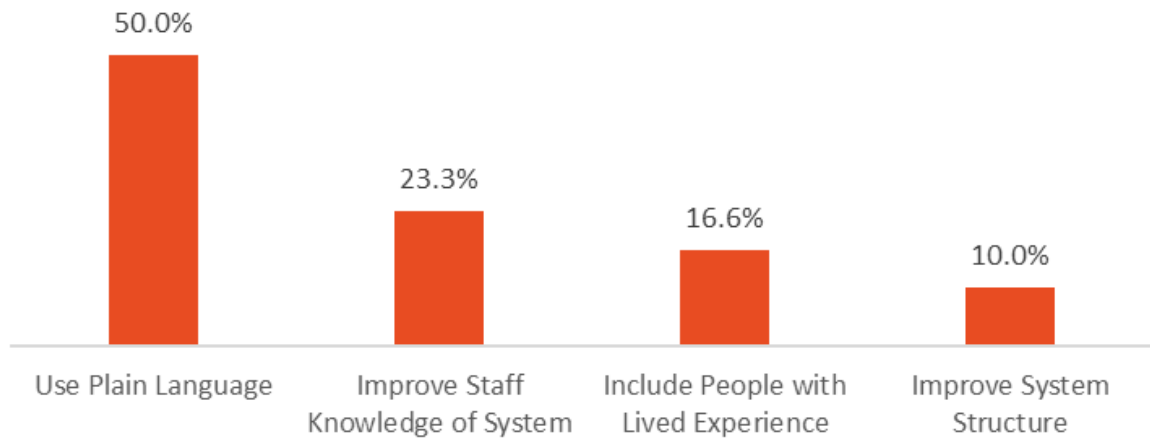
Focus Group Findings

Key findings from the focus group are incorporated into the report. The charts below provide additional detail on some of the focus group responses.



Self-Advocate Recommendations to Improve Access to Information

(Number of Self-Advocates = 37)



Appendix D: Family and Self-Advocate Online Survey

An online survey was created for families and self-advocates to inform the assessment of people's experiences when looking for information and the usefulness once the information was found. The survey gathered information on where they look for information and the availability, accessibility and usefulness of information in those places. The on-line survey design was adapted based on recommendations provided by the project workgroup and insight gained from the environmental scan and focus groups.

Survey Design and Administration

HSRI and PPD at VCU provided technical assistance for questions and survey format. Answer options were designed for gaining the most effective insight, data and information from respondents.

The survey was distributed through advocacy organizations, I/DD associations and other stakeholder networks. Facebook and other social media platforms, e-mail networks and newsletters were utilized to announce the survey. The survey was also translated into Spanish by VCU and made available through social media, direct email distribution and on websites of project partners.

The Arc of Virginia/ALLY Alliance assisted with survey distribution to ensure as many self-advocates as possible were provided an opportunity to participate. Follow-up for assistance or support needed to complete the survey was also provided.

Questions for Family Survey

We are interested in learning about information that is the most helpful to you in supporting your family member.

1. Have you ever tried to get information about services for your family member from any of the following? Check YES to any place you have ever used to find that information.
 - County government** (For example Community Services Board (CSB) or County Social Service office, or County Health department)
 - State government** (For example DMAS, DBHDS, or No Wrong Door program)
 - Private advocacy organization** (For example, The Arc of Virginia)
 - Agency that provides services to people with IDD/DD** (For example, employment, residential, day, after school programs)
 - Doctor's office**
 - Education system or School-based resources** (For example Parent Resource Center, School Transition Coordinator, Special Education Advisory Committee (SEAC) _
 - Parent support organizations disability-based associations:** (For example Center for Family Involvement, Autism Societies, Down Syndrome Associations)

- Center for Independent Living (CIL)** (for example the EnDependence Center of Tidewater or EnDependence of Northern Virginia)
 - Informal family groups/Other families**
2. Which of these have you used to find information from this organization:
- Website
 - Phone call
 - Social Media
 - Review of written material
 - Other (limit to 25 characters)
3. For each of the above examples checked YES; how useful was the information you discovered? Use a range of 1 being not at all useful to 5 being very useful.
- Not at all useful
 - A little useful
 - Somewhat useful
 - Useful
 - Very useful
 - Not Applicable: I have not yet found the information I need.
4. FOR THE YES ANSWERS TO WEBSITE QUESTIONS: How easy was it to navigate the website?
- Very Difficult
 - Difficult
 - Neither easy nor difficult
 - Easy
 - Very easy
5. Thinking of all the places you have looked for information, please name one source of information that you have found to be the most useful (limit characters to less than 100)
6. Please check all of the things that make information useful to you: (check all that apply)
- Easy to understand –it is delivered in plain everyday language
 - Easy to follow instructions --- the steps are simple and do not cause confusion
 - Accurate explanations--information is correct
 - Consistent information --- the information shared is the same over time, or the same between places or people who share it
 - Preferred language – information is made available with an option for my primary language
 - Other - please record here: (limit to 100 characters)
7. Please share any changes that you think would improve the usefulness of information about I/DD services in Virginia?

8. The following questions are collected because the grant project wants to be sure we reach people from all ethnic and racial backgrounds to participate in the project. You are welcome to answer these questions, but you can also say that you prefer not to answer any of these questions. This section asks about YOUR FAMILY MEMBER with an intellectual or developmental disability.
9. What is the age of your family member with an intellectual or developmental disability?
 - 0 - 3-Year-Old
 - 4 - 6-year-old
 - 7 - 14-year-old
 - 15 - 22-year-old
 - 22- 35-year-old
 - 35 - 60-year-old
 - 61+ years old

Questions for Self-Advocate Survey

1. Please tell us where you most often go to find information about services and resources. Pick all that apply.
 - County Office-** Community Services Board (CSB) or County Social Service office, or County Health Department
 - State Office- government** (For example DMAS, DBHDS, or No Wrong Door program)
 - Private advocacy organization** (For example, The Arc of Virginia, Ally Alliance)
 - Agency that provides services to people with IDD/DD** (For example employment, residential, or day services provider.
 - Doctor or Medical office**
 - Education system or School-based resources** (For example School Transition Coordinator
 - Self -Advocate support organizations disability-based associations:** (For example, ALLY Alliance, Center for Family Involvement, Autism Associations, Down Syndrome Associations
 - Center for Independent Living (CIL)** (for example the EnDependence Center of Tidewater or EnDependence of Northern Virginia)
 - Other**
2. **For the organizations that you picked in Question 1 how do usually get the information.** PICK ALL THAT APPLY
 - Website
 - Social Media Page
 - Phone Call
 - Webinar
 - Meeting

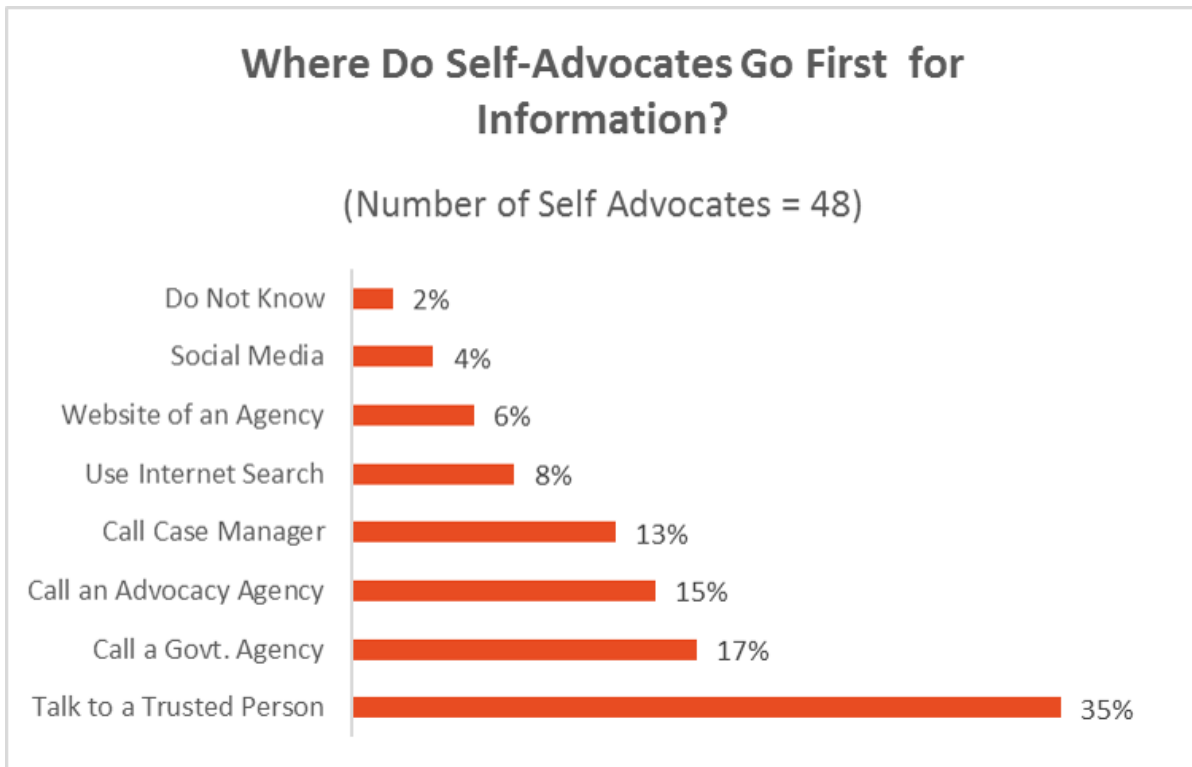
- Attending a Support Group
- Brochure
- Other

3. What is it that makes information in the places you selected above easy to understand and useful to you? PICK ALL THAT APPLY

- Plain Language (for example, no jargon, written in a way I could understand)
- Speaking to a person (for example, a person who was helpful, called you back)
- Accessibility features on websites (for example, enlarge the text/words, or closed captioning)
- Easy to find on a website (for example, icons, pictures, or links took you straight to the information)
- Explained by a person (the person explained what you needed to do next)

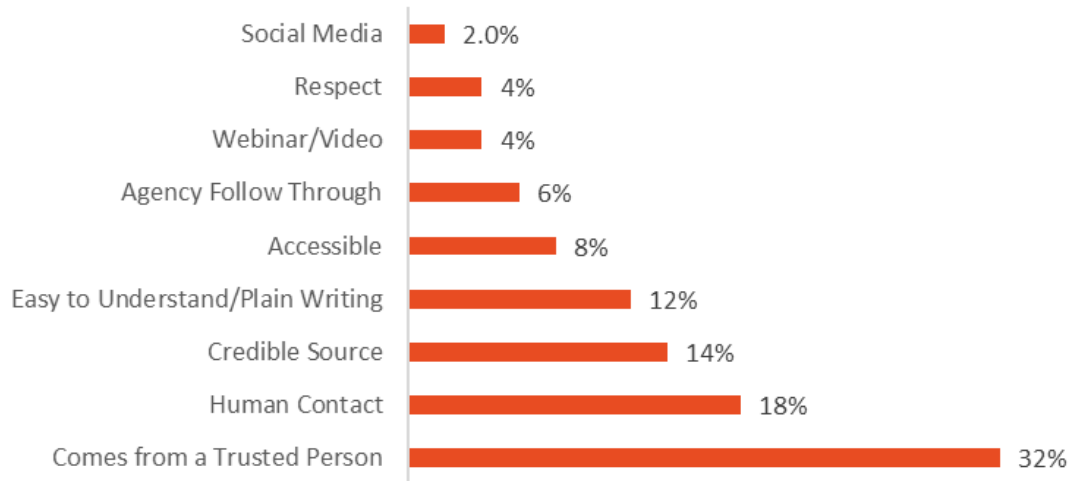
Survey Findings

Key findings from the surveys are incorporated into the report. The charts below provide additional detail on some of the surveys responses.

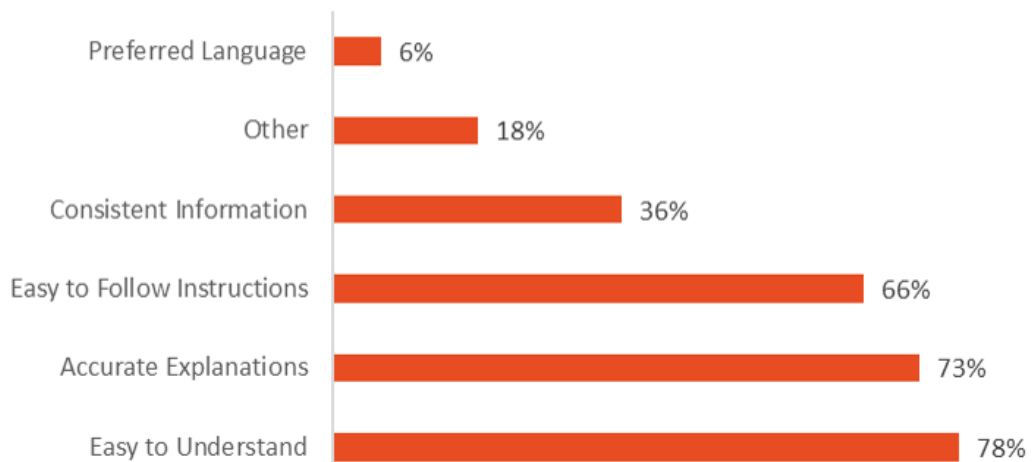


What Makes Information Useful for Self-Advocates?

(Number of Self-Advocates = 50)



Family Members' Top Factors for Useful Information



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