



Assessment of Virginia's Disability Services System:

Information Ecology of the Disability Services System



2024 Assessment of Virginia's Information Ecology of the Disability Services System

First Edition

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

Virginia Board for People with Disabilities

Ratcliffe Building
1602 Rolling Hills Drive, Suite 100
Richmond, VA 23229

804-786-0016
800-846-4464 (Toll-free)
804-786-1118 (Fax)
email: info@vbpd.virginia.gov
www.vbpd.virginia.gov

Funding for this project/product was supported, in part, by the Virginia Board for People with Disabilities, under grant number 2301VASCDD, from the U.S. Administration for Community Living (ACL), Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.

The Virginia Board for People with Disabilities would like to thank all the agencies, organizations and others who contributed data and information to this assessment.

VBPD Chair

Niki Zimmerman

VBPD Executive Director

Teri Morgan

Authors

Dr. Myeong Lee, George Mason University

Latifah Abubakr, George Mason University

Tulsi Shrivastava, George Mason University

Julia H.P. Hsu, George Mason University

Dr. Samantha A. Whitman, Arizona State University

Pyeonghwa Kim, Syracuse University

Research Contributors

Victoria Gonzales • Dr. Kathleen H. Pine

Editing

Linh Thi Nguyen, Manager of Special Projects & Priority Initiatives

Anita Ayres, Communications & Information Manager

Design

Brittany Hughes, Communications Assistant

***Special thanks to the members of the Virginia Board for People with Disabilities
Assessment Ad Hoc Committee***

Allison Coles-Johnson • Samantha Hollins • Richard Kriner

Deanna Parker • Matthew Shapiro



COMMONWEALTH OF VIRGINIA
Virginia Board for People with Disabilities

Dennis Findley
Chair
Allison Coles-Johnson
Vice Chair
Mary Vought
Secretary
Teri Morgan
Executive Director

Ratcliffe Building
1602 Rolling Hills Drive, Suite 100
Richmond, Virginia 23229

Virginia Relay or Call 711
800-846-4464(Ph);
804-786-1118(Fax)
info@vbpd.virginia.gov
www.vbpd.virginia.gov

August 1, 2024

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

The Board selected Information Ecology of the Disability Services System as a topic area to be assessed in 2024. This topic area builds on the Board's 2022 assessment on Access to Information for People with Disabilities and their Family Members. The research in this assessment was conducted by George Mason University's Dr. Myeong Lee and his team. Based on their findings, the Board makes recommendations to improve information management practices among state disability agencies.

We appreciate the assistance of the state agencies and other stakeholders that provided information and clarification on their information management practices and staff challenges. The policy recommendations included in this assessment were developed by an ad hoc committee of the Board and approved by the full Board at its June 4, 2024, meeting.

Table of Contents

<i>Statement of Values</i>	1
<i>Executive Summary</i>	2
Recommendations Related to the State’s Consistency Management	2
Recommendations Related to Visibility and Strategic Management at Local Agencies	3
Recommendations Related to Enhanced Information Networks between Governmental Agencies	3
Recommendations Related to Improved Network between Non-Governmental and Governmental Providers	3
Recommendations Related to Supporting the Creation of a Stigma-Free Environment	4
Recommendations Related to Improving the Capacity of Government Information Sources while Providing an Easy Validation Method for Non-Governmental Information	4
<i>Background</i>	5
Information Ecology	5
Project Goals and Research Process	5
Interviews	5
Surveys.....	6
<i>Findings and Recommendations</i>	7
State Consistency Management Plans	7
Inconsistent Practices to Update Information.....	7
Gaps in Staff Turnover and Institutional Changes	7
Decentralization in Policies and Information Strategies	8
Technology Management and Adoption Issue	9
Misinformation and Rectifying Efforts.....	9
Visibility and Strategic Management at Local Agencies	10
Organizational Tension between Defined Work and Care Work.....	10
Enhanced Information Networks Between Governmental Agencies	11

Lack of Information Network with Other Agencies	11
A Holistic View of Providers' Information Sharing Network.....	12
Improve the Network of Non-Governmental and Governmental Providers	14
Heightened Roles as “Information Brokers”	14
Information Validation Work.....	15
Fragmented Input from Different Agencies.....	15
Increased Outreach & Campaigns	15
Creation of a Stigma-Free Environment.....	16
Relationship and Trust Building by Balancing Stigma, Empathy and Organizational Identification.....	16
Reputation Management Work.....	17
Characteristics of Frequently Used Information Sources.....	17
Improve the Capacity of Government Information Sources while Providing an Easy Validation Method for Non-Governmental Information	19
<i>Appendix A: Interview Protocol</i>	<i>21</i>
General Questions.....	21
Information Challenges When Delivering Services to Clients.....	21
Types of Information They Handle	21
Current Way of Providing Information	22
Management + Flow of Information	22
Reflection	23
<i>Appendix B: Survey Protocol.....</i>	<i>24</i>
The Provider Survey: Survey for Providers.....	24
Providing Information.....	24
Providing Information to Individuals and Families	25
Providing Information to Government and Non-governmental Organizations	25
Receiving / Seeking Information.....	27
The User Survey: Survey for People with Disabilities or Their Family Members	28
<i>Appendix C: Interviewee Demographics</i>	<i>34</i>

State	34
Local.....	34
Nonprofit/For-Profit.....	35
<i>Appendix D: Demographic and Organizational Characteristics of Survey Respondents</i>	37
<i>Appendix E: Providers' Information Networks.....</i>	39
<i>Appendix F: Implications for Assessing the Fragmentation of Information.....</i>	43
<i>Appendix G: Frequently Used Information Sources by Demographic Groups</i>	44
<i>Works Cited.....</i>	48

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 ... [H]istorically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem ..."

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

The Virginia Board for People with Disabilities serves as Virginia's Developmental Disabilities Council. In this capacity, the Board advises the Governor, the Secretary of Health and Human Resources, federal and state legislators, and other constituent groups on issues important to people with disabilities in the Commonwealth. The following assessment of the information ecology of the disability services system is intended to serve as a guide for policymakers who are interested in ensuring that people with disabilities live fully integrated lives in their communities, with the supports they need, based on their interests and lifestyle choices. The Board's work in this area is driven by its vision, values and the following core beliefs and principles:

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

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

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

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

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

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

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

Executive Summary

Access to disability services information depends on many factors, from an individual's digital literacy, social connections and physical mobility to the interface design of websites. However, it is also true that the availability of disability services information (e.g., how to apply for a Medicaid Waiver) and how such information is managed and provided to end users in Virginia are also critical factors that shape people's information access. This assessment focuses on understanding the latter, namely, the "information ecology" of disability services in Virginia. Specifically, we examine how service providers, both governmental and non-governmental agencies, manage information about disability services, the challenges staff face in providing information, and how different types of information are communicated and shared across different providers.

Findings based on survey and interview data analysis suggest that service providers in different sectors face common challenges in managing and providing information to people with disabilities and their family members. Still, providers also must deal with unique challenges specific to their service sectors. For example, common challenges in managing and providing information include language barriers, community outreach to underrepresented groups, misinformation and resource constraints. Meanwhile, state agencies reported that they found it difficult to manage and provide information consistently due to staff turnover, inconsistent workflows and varying use of information systems. Local agencies, such as Community Services Boards (CSBs), often took on additional work as they provided information to people from other jurisdictions or states. Non-governmental agencies, such as nonprofits and advocacy organizations, often became a first-stop shop for any informational queries, as many people found it easier to contact non-governmental agencies rather than go directly to governmental agencies.

Within the information ecology of disability services, diverse providers play different roles in providing information about disability services while sometimes being disconnected from each other, creating "information silos." We developed recommendations to reduce the managerial and ecological issues hindering people's information access.

Implementing these recommendations would help the Commonwealth continue to improve the management of key information in Virginia, allowing people to have consistent access to information through diverse channels.

Recommendations Related to the State's Consistency Management

1. The General Assembly should endorse and fund the design, development and implementation of information systems and/or playbooks at relevant state agencies that provide information about disability services in the Health and Human Resources

Secretariat. This approach would facilitate smoother staff transitions and ensure that agencies maintain consistent quality of their information services despite staff turnover.

2. The General Assembly should endorse and fund the design, development and implementation of an automated information system to monitor and notify staff of policy or regulatory changes. The form of the information system could be a dashboard, email alert system or an alert module embedded in the state's internal information systems.
3. The Department of Human Resource Management (DHRM) should work with the Office of Data Governance and Analytics to develop information quality validation training for state employees.

Recommendations Related to Visibility and Strategic Management at Local Agencies

4. The Community Services Boards (CSBs), Department of Social Services (DSS), Virginia Department of Health (VDH) and Department of Behavioral Health and Developmental Services (DBHDS) should increase the visibility and strategic discussion about types of work (both care work and defined work) conducted at local agencies.

Recommendations Related to Enhanced Information Networks between Governmental Agencies

5. The Department of Behavioral Health and Developmental Services (DBHDS), with support from the Department of Medical Assistance Services (DMAS), should develop and implement innovative strategies for information networks that facilitate efficient communication and data validation between local agencies (e.g., CSBs), and between local and state agencies. These networks should enhance access to accurate information, streamline the validation process and enable the sharing of best practices.
6. The Department of Behavioral Health and Developmental Services (DBHDS) should support the establishment of a monthly forum or ongoing chat room where support coordinators can share best practices, raise concerns and answer common questions. This will allow local agencies to share their key networks of information providers with other agencies.

Recommendations Related to Improved Network between Non-Governmental and Governmental Providers

7. Virginia's No Wrong Door system should be enhanced to better support providers and payers of disability-related information by implementing a single validation tool for advanced information systems. This advancement will streamline access by encouraging providers to update their service information through a standardized channel. It will also enable the cross-sharing of data, populating multiple resource databases to enhance the accuracy and reliability of information.

Recommendations Related to Supporting the Creation of a Stigma-Free Environment

8. The Department of Medical Assistance Services (DMAS), Department of Behavioral Health and Developmental Services (DBHDS), Department of Social Services (DSS) and Virginia Department of Health (VDH), in coordination with the stakeholder community, should collaboratively develop and implement strategies for creating a stigma-free atmosphere to mitigate information access issues.

Recommendations Related to Improving the Capacity of Government Information Sources while Providing an Easy Validation Method for Non-Governmental Information

9. The Department of Medical Assistance Services (DMAS), Department of Behavioral Health and Developmental Services (DBHDS) and Department of Social Services (DSS), in coordination with the government-initiated resources and initiatives, should collaboratively develop and implement strategies for improving the capacity and awareness of their information services (e.g., the number of frontline staff, promotion of existing information systems), because people of diverse backgrounds and regions heavily use government resources as their main information sources, while not being aware of certain government-sponsored websites (e.g., No Wrong Door).
10. Because many people with disabilities and their family members acquire disability services information through Google searches, non-governmental agencies, websites and social media, the Department of Behavioral Health and Developmental Services (DBHDS) and the Department of Medical Assistance Services (DMAS) should take proactive action to increase the monitoring of information provided by these sources to mitigate misinformation or any conflicting information provided by different sources.

Background

Information Ecology

Information ecology refers to the arrangement of information sources, users, providers and how they share information at the community level (e.g., an information source is an item or tool such as a website or book, while an information provider is an organization). This information ecology determines people's overall access to necessary information (Lee et al., 2019; Nardi & O'Day, 2000). Many research studies have focused on individual-level problems such as the digital divide, information literacy and system usability when discussing people's access to information. Without addressing the complexity of the information ecology, however, the responsibility of finding necessary information will continue to fall on people with disabilities and their families, negatively impacting their quality of life. Because ecological issues in people's information access (e.g., insular information sharing within ethnic groups, people's sole reliance on a certain information source) are different from individual-level issues, they need to be addressed separately.

Project Goals and Research Process

We aimed to **understand structural and managerial issues** that could prevent people's access to information about disability-related services (with a focus on Medicaid services) and to **make recommendations** to help address these issues. Specifically, we aimed to provide a comprehensive analysis of the information ecology of disability services through in-depth research on information sources, key organizations and their users.

Overall, our approach included (1) snowball sampling-based interview data collection, (2) an abductive approach to analyze the interview data, (3) large-scale surveys to understand what information sources are available and used, (4) network analysis to measure the fragmentation of information, and (5) network visualization of the information ecology.

Interviews

For the interview data collection, snowball sampling was the best approach (Robinson, 2014). Our team first interviewed agencies and individuals that previously partnered with the Board. From there, the interviewees referred our team to additional providers across Virginia via direct email. We interviewed employees from state and local government, non-profit organizations and for-profit organizations, including both urban and rural settings. We focused on interviewing frontline workers who worked directly with people with disabilities and managed a caseload, but we did not exclude individuals who held high-level roles within their organizations (e.g., directors, program managers, CEOs).

We conducted 60 interviews with 61 individuals from disability-related service providers, shown in [Appendix C](#). Interviewees included 19 Virginia state government agencies, 17 local government agencies (e.g., CSBs) and 25 non-government agencies (e.g., nonprofits and for-profits). We asked interviewees about their experiences and perspectives in providing disability-related service information in Virginia (see [Appendix A](#)).

Our team recorded and transcribed each interview. We then analyzed the interviews using the abductive approach. The abductive approach uses theory to understand what people say. Additionally, this approach captures key challenges and themes emerging from the data without using theory (Tavory & Timmermans, 2014). After reading the transcripts, we identified statements of interest and identified common themes.

[Figure 1](#) illustrates the locations of the agencies and providers we interviewed, and their geographical service coverage. The coverage of state-wide agencies is not visualized on the map.

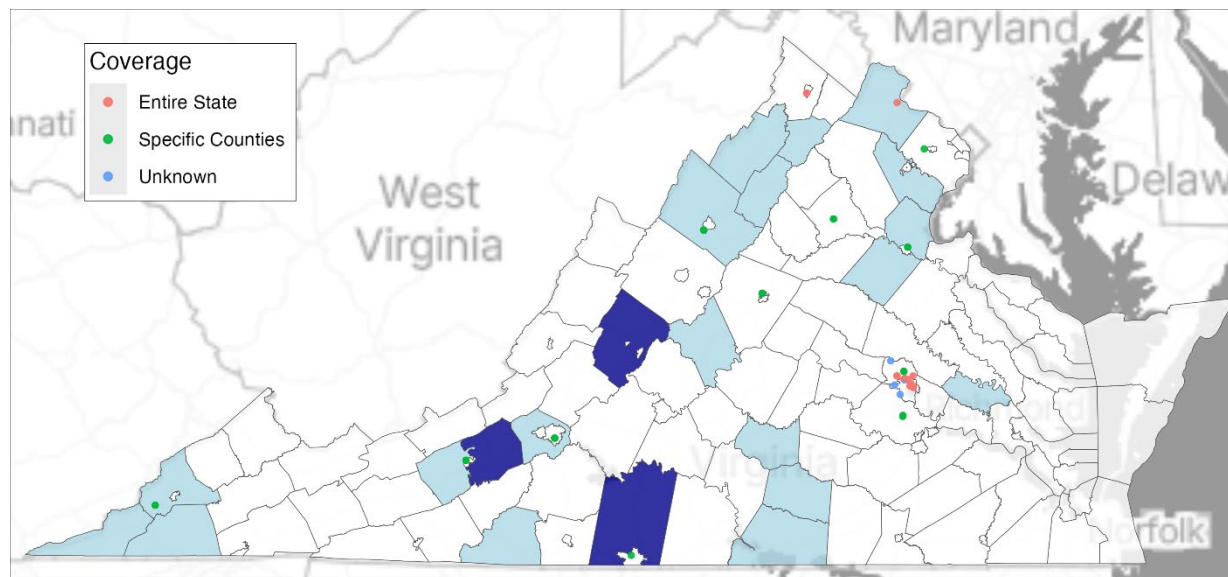


Figure 1. The locations of the interviewed providers and their geographical coverage.

Surveys

We designed two surveys, one for disability service providers and the other for service users (i.e., people with disabilities and their family members). For the Provider Survey, our primary goal was to identify the types of information they provide to other organizations and individuals and examine the top organizations that serve as information sources for these providers. For the User Survey, we focused on identifying the information sources and key organizations that people with disabilities and their family members use to seek and find information about disability-related services (see [Appendix B](#) for the survey questionnaire).

95 respondents completed the Provider Survey. 887 respondents completed the User Survey. The demographic information and characteristics of the survey respondents are presented in [Appendix D](#). The User Survey samples are relatively skewed towards proficient English speakers (98% of the respondents compared to 94% of all Virginians), females (77% of respondents compared to 50.7% of all Virginians) and those with high digital literacy and internet access (95% of respondents). Meanwhile, age, insurance coverage, geographical regions (urban vs.

rural), ethnicity (white vs. non-white) and income range across different respondent groups are relatively well-balanced.

Findings and Recommendations

State Consistency Management Plans

Our interview analysis suggests that core information challenges for state-level agencies are institutional in nature. State-level challenges make it hard to consistently provide disability-related information and services. The leading causes for inconsistent information management range from technology use/adoption and information update methods to staff turnover. This observation led us to make recommendations for developing consistent management plans.

Inconsistent Practices to Update Information

Virginia’s disability agencies struggle to establish structured processes for updating and maintaining information on websites or databases. The absence of standardized guidelines results in inconsistent updating practices by state employees, which make it hard for people with disabilities and their families to find up-to-date information.

Gaps in Staff Turnover and Institutional Changes

Trained employees frequently leave the agency. The employees who do not leave often find it difficult to meet changes in regulatory expectations. Both staff turnover and regulatory or institutional changes make it hard for staff to provide consistent information services to people with disabilities and their families. For example, a staff member from a state agency explained,

“If they [Community Services Boards] add more to what the policies and procedures have, then they are bound to follow their own policies and procedures, which are not consistent for the board or even for providers. ... Then support coordinators leave, and history changes, and things move forward, and old documents don’t get thrown away because even though we update the website, the support coordinator who has stashed it in her desk, who was usin’ the same form that she’s used forever because that was the form she used, may not have thrown it away.”

These observations led us to develop Recommendation 1, which focuses on improving the management of staff turnover through information systems and playbooks.

Recommendation 1: Enhance Staff Turnover Management Through Customized Information Systems and Playbooks

The General Assembly should endorse and fund the design, development and implementation of information systems and/or playbooks at relevant state agencies that provide information about disability services in the Health and Human Resources Secretariat.
--

Recommendation 1: Enhance Staff Turnover Management Through Customized Information Systems and Playbooks (Continued)

This approach would facilitate smoother staff transitions and ensure that agencies maintain consistent quality of their information services despite staff turnover. Specifically, we suggest:

- **Optimization of the Commonwealth of Virginia Learning Center:** Use the Learning Center to expedite the onboarding process for new employees. This could include integrated modules that outline core work practices that would apply across the system, such as using standardized information sources and their interpretations.
- **Creation of Customized Playbooks:** Develop playbooks focused on critical aspects of information management, such as updating system data and locating necessary resources. These playbooks should be tailor-made to reflect the unique needs and contexts of each department and include a directory of organizations that can be referred to for various topics (which can be updated easily).

Contextualized and Nuanced Support Mechanisms: Beyond basic training, it's crucial that these tools offer detailed guidance on key resources, effective communication practices and the interpretation of information. This will ensure that new staff members are not only trained but also fully integrated into their roles with a deep understanding of their operational environment.

Beyond training for staff members and support for staff turnover, organizational factors affect the consistency of information management, such as frequent changes in policies and related information, which led us to make Recommendations 2 and 3.

Decentralization in Policies and Information Strategies

Due to each agency's unique policies and work practices, decentralized operations result in variability in policy interpretations, inconsistent input to centralized systems and differing information meanings. This makes it hard for staff to provide consistent information services to people with disabilities and their families. Therefore, we recommend supporting the implementation of an automated information system for automatically monitoring policies and regulations.

Technology Management and Adoption Issue

Also, agencies have difficulties managing digital information due to the need for extra IT expertise and poor design of information management tools. As a result, some staff members often choose not to use technologies (e.g., information systems, digital tools) available in their agencies, making it hard for the agencies to manage information through technology in a consistent manner. This issue is closely related to staff members' familiarity with and intention to adopt technological systems or tools.

Recommendation 2: Implement Automated Information Systems for Policy and Regulation Tracking

The General Assembly should endorse and fund the design, development and implementation of an automated information system to monitor and notify staff of policy or regulatory changes. The form of the information system could be a dashboard, email alert system or an alert module embedded in the state's internal information systems. Key details include:

- **System Characteristics:** The automated information systems should (1) promptly notify staff of policy changes, and (2) detect policy changes accurately and in real-time.
- **Technology Workgroup Formation:** Establish a technology workgroup to explore the specific solutions, including the potential use of artificial intelligence (AI) for system searches, and the potential risks of each possible solution. This workgroup should include state agency heads (or designees) and George Mason University, to ensure that the solutions best meet agency needs, and that the workgroup's solutions align with the research published in this assessment.
- **Technology Adoption Initiative by State Agency Heads:** Encourage state agency heads to develop a technology adoption initiative aimed at enhancing employee engagement with technology and related systems in their work. The initiatives could include technology training programs or on-the-job-training-type workgroups.

Misinformation and Rectifying Efforts

Prevailing misinformation on social media and the unintentional provision of misinformation creates challenges for staff members. Staff must correct misinformation and also take on additional work to address the emotions of people with disabilities and their family members when they are frustrated due to misinformation. This led us to develop Recommendation 3, which focuses on improving state employees' ability to validate information quality.

Recommendation 3: Implement Information Quality Validation Training for State Employees

The Department of Human Resource Management (DHRM) should work with the Office of Data Governance and Analytics to develop **information quality validation training** for state employees.

This recommendation will be more effective when implemented in parallel with the real-time detection of policy changes, as specified in Recommendation 2.

Visibility and Strategic Management at Local Agencies

Through our interviews, we found that local-level providers have information and managerial challenges related to “defined work” and “care work.”

Organizational Tension between Defined Work and Care Work

“Defined work” refers to codified job duties officially expected for the position. Conversely, “care work” is work that is usually outside of defined work (England, 2005). For example, staff members at local providers often listen to a person’s frustration before providing services or provide information to people from outside of Virginia. These types of work are all part of caring for others, regardless of their defined job duties. Staff often had to (or chose to) do care work, sometimes in order to accomplish their defined work (e.g., they cannot provide service information properly without alleviating the information seeker’s frustration). For example, a support coordinator from a regional Community Services Board (CSB) shared the heavy emotional labor often associated with the tasks and responsibilities of an intensely demanding job:

“I worry about the people that I support. I care so much. I wish I could separate it. It’s very challenging.”

From an organizational perspective, directors may need to manage the tension between staff care work and defined work, as care work and defined work are often intertwined. Staff work is also closely related to the use of limited resources allocated for their organizations, performance measures and organizational reputation.

Also, the large volume of paperwork and regulatory tasks required for each program participant, particularly those eligible for or on Medicaid, creates additional duties for staff members, such as keeping track of several timelines, updates and client records. These heightened workloads often make it hard to consistently conduct both care work and defined work together. A support coordinator from a regional CSB described the nature of case management:

“The caseloads are definitely way too high to keep track of everything, to follow up, because it’s not just finding a provider and linking them to the service. It’s all the paperwork that goes with it. Making sure things are done correctly because everything flows through us.”

The invisibility of staff members’ care work, intensified by increasingly high caseloads per case manager, highlights the need for systemic solutions to support their information management work. Thus, Recommendation 4 focuses on enhancing visibility and the strategic management of work practices based on increased accountability:

Recommendation 4: Enhance Visibility and Strategic Management of Work Types at Local Agencies

The Community Service Boards (CSBs), Department of Social Services (DSS), Virginia Department of Health (VDH) and Department of Behavioral Health and Developmental Services (DBHDS) should increase the visibility and strategic discussion about types of work (both care work and defined work) conducted at local agencies.

- **Redesigning Work Structure:** Some of the care work (e.g., listening to a person’s frustration before providing services, providing information to people from outside of Virginia) could be systematized as defined work or transferred to other dedicated providers (if any).
- **Resource Allocation:** Based on an understanding of the variety of work being done in local agencies, the state agencies and CSBs can more strategically allocate resources to support both care work and defined work.

[Enhanced Information Networks Between Governmental Agencies](#)

Both the interview analysis and the survey-based network analysis showed that there are discrepancies in local and non-governmental providers’ information sharing practices due to a lack of consistent information networks between providers.

[Lack of Information Network with Other Agencies](#)

In interviews, staff members from local providers stated that they often relied on trusted and knowledgeable personal networks when validating and looking for specific disability-related information. Staff reliance on personal networks is partly because staff have limited access to centralized information networks and peer institutions (e.g., CSBs from other regions). The limited access and connections increased local provider workload and perpetuated the variation in the interpretation of policy and regulatory information.

A Holistic View of Providers' Information Sharing Network

To better understand how providers share disability-related information with each other, the Provider Survey asked about (1) to which agencies or technologies the providers share information and (2) from which agencies or technologies providers seek or receive information. Using the responses to the Provider Survey, we constructed information sharing networks (i.e., information ecology), which show a network of agencies when they exchange any disability-related information. The overall network of the providers' information sharing patterns is presented in [Appendix E](#).

Results from the network analysis of the overall information sharing patterns show that non-governmental agencies and websites play key roles in the information ecology of disability services ([Table E1](#)). Meanwhile, state agencies, such as DMAS and DBHDS, and local CSBs are key players in maintaining, gathering and providing information to other agencies and websites. Also, advocacy agencies such as the Arc of Virginia are highly ranked in terms of providing information to other agencies ([Table E1](#)).

[Figure 2](#) visualizes the information sharing network of Medicaid-related information only. The blue dots represent information providers (i.e., agencies and organizations). The size of the dot shows the amount or diversity of information that the information provider holds. When one provider shares information with the other, an arrow connects the two providers. The thickness of an arrow represents the amount or frequency of information sharing. Based on the arrows between providers, it is possible to see how disability-related information flows across the providers at the ecological level. [Figure 2](#) shows that the information ecology of agencies and organizations is more fragmented regarding Medicaid-related information (i.e., they are less likely to share Medicaid information with other agencies or organizations) compared to the information ecology of providers who share all kinds of disability-related information. This means that there are multiple silos in the Medicaid information ecology where some agencies are not connected well with some major "information hubs."



Figure 2. Information sharing/provision networks focused on Medicaid information.

When it comes to Medicaid information, many non-governmental agencies play an important role. For example, Wall Residences, a private organization, plays a key role in finding and receiving Medicaid-related information from other agencies, which potentially indicates that Wall Residences might serve a broader population on behalf of other agencies. Next Step Success, LLC, ranked number two in a bridging role among the providers. This ranking indicates they serve as a bridge and actively transfer, mediate or interpret Medicaid-related information between different agencies. ([Table E2](#), [Appendix E](#) provides a detailed overview of the providers' roles in the Medicaid information ecology.)

Based on these ecological characteristics, the network analysis, along with the interview-based findings on a lack of information networks, emphasizes the need for an increased network between local agencies and between local and state-level agencies, as, without central state agencies, the information ecology of disability services could be fragile. In other words, if major state agencies' communications fall short, the rest of the agencies in the network will face confusion and a loss of connections in providing and receiving information.

Recommendation 5: Innovative Strategies for Information Networks

The Department of Behavioral Health and Developmental Services (DBHDS), with support from the Department of Medical Assistance Services (DMAS), should develop and implement innovative strategies for information networks that facilitate efficient communication and data validation between local agencies (e.g. CSBs), and between local and state agencies. These networks should enhance access to accurate information, streamline the validation process and enable the sharing of best practices.

- **Formalizing Information Networks:** DBHDS can support and formalize information networks between state and local agencies to better share their information. The formalized information network may include but not be limited to (1) new information systems that reflect local agencies' information and communication needs and (2) dedicated personnel (e.g., a new position within DBHDS and CSBs for managing inter-organizational communication).

Recommendation 6: Leverage Staff Knowledge and Networks

The Department of Behavioral Health and Developmental Services (DBHDS) should support the establishment of a monthly forum or ongoing chat room where support coordinators can share best practices, raise concerns and answer common questions. This will allow local agencies to share their key networks of information providers with other agencies.

[Improve the Network of Non-Governmental and Governmental Providers](#)

The information challenges faced by non-governmental providers often stem from their roles as information brokers and trust builders. Accordingly, we developed recommendations to support providers' roles within the information ecology of disability services in Virginia.

[Heightened Roles as "Information Brokers"](#)

An "information broker" is someone who provides information services that are not specific to their organization. For example, a non-profit may listen to the needs of an individual and refer them to a local Community Services Board (CSB) to make Medicaid-related queries. While this

type of information brokering work happens at all levels of agencies, this role was salient in non-governmental providers.

According to our interviews, many people with disabilities and family members use non-governmental agencies as “first-stop shops.” This might be due to (1) better accessibility, (2) long-term engagement and trust, (3) loose organizational rigidity (e.g., communication protocols are less formal), and (4) organizational identification that aligns with their needs (e.g., the name of the agency directly reflects people’s needs, such as “Virginia Down Syndrome Association”). Because information brokering work is less likely to be the organization’s primary service, this may increase their management challenges.

Information Validation Work

Because non-governmental agencies have been increasingly taking on information brokering roles, they have had to focus on information validation intensively. The agencies often validated the accuracy of policies and resources to provide high-quality information to people with disabilities and their family members, even if that information is not about their organization’s services. This additional work may have increased their workload, complicating their information management practices.

Fragmented Input from Different Agencies

When tasked with finding an answer to their disability-related queries, individuals with disabilities and providers alike are faced with varying pieces of information from different key agencies, resulting in more confusion. After navigating through multiple information sources and encountering conflicting information, information users are often on the verge of giving up. When asked about the challenges faced when delivering disability services, a transition coordinator from a nonprofit agency described her experience, which was echoed by several of the interview participants:

“It’s confusing [and] frustrating for anyone, but then when you mix a disability, ... it just compounds it ... A lot of times the information might be incorrect because it depends on who you talk to ... There’s some overlap of services, but at the same time, ... there’s a lot of fragmentation, and it can be very frustrating as a consumer [and] as a provider.”

Inconsistent information hinders the ability of staff to quickly provide accurate information, as they consider accuracy and manage state agencies’ reputations while handling their own workload.

Increased Outreach & Campaigns

As our network analysis of providers’ Medicaid information sharing shows (see [Appendix E](#)), state agencies such as DMAS and DBHDS still play key roles in the flow of disability-related information across non-governmental agencies. Therefore, state agencies, in collaboration with CSBs, need to allocate more resources to play a leadership role among different types of agencies (especially as an information interpreter). Otherwise, there could be standardization and interpretation issues, combined with the dissemination of information.

Recommendation 7: Enhance Virginia’s No Wrong Door System for Improved Disability-Related Information Access

Virginia’s No Wrong Door system should be enhanced to better support providers and payers of disability-related information by implementing a single validation tool for advanced information systems. This advancement will streamline access by encouraging providers to update their service information through a standardized channel. It will also enable the cross-sharing of data, populating multiple resource databases to enhance the accuracy and reliability of information. This enhancement will reduce reliance on inefficient methods such as internet searches or direct inquiries with organizations, which can be time-consuming and yield inaccurate information.

- Centralized Repository:** A centralized repository consisting of various statewide resource databases to support information brokering among providers (i.e., referring or validating disability service information for clients that’s not specific to their organization), which facilitates access to necessary information by people with disabilities, family members, caregivers and loved ones, supporting partnership and elevating trust.

Creation of a Stigma-Free Environment

The findings from both interviews and the User Survey analysis suggest that trust, stigma and the quality of relationship play key roles in shaping people’s use of information sources, and thus their access to information.

Relationship and Trust Building by Balancing Stigma, Empathy and Organizational Identification

Non-governmental providers put major efforts into building trust and maintaining relationships with people with disabilities and their families. They put significant efforts into sustaining partnerships with diverse communities, care about people’s potential fear of accessing organizations, and sometimes implement “cultural brokers” to translate information into languages tailored to the communities and better engage with them. Because some people with disabilities and their family members had a fear of stigma (e.g., asking for help could be seen as shameful) and government agencies (e.g., not being prepared to talk to authorities), providers often put efforts into mitigating these fears through deep engagement and loosening organizational rigidity (e.g., keeping communication protocols informal and open). For example, an Independent Living Specialist of a nonprofit underscored the importance of trust in ensuring healthy communication in information sharing with the individuals she serves:

“There’s a perception of a lot of judgment [of] right or wrong. If you’re asking for help, you shouldn’t be asking for help, and why are you not working if you don’t look like you physically can’t work ... Establishing that trust is first and foremost, because if you don’t establish trust and rapport with a consumer or their family, you don’t have anything.”

Reputation Management Work

A few interviewees mentioned that people sometimes showed distrust toward authoritative systems. In that case, providers managed the reputation of the entire service system by providing resources and justifications for any misunderstanding. This management of reputation went beyond their organizations, as it was important for the providers to maintain a similar trust level toward other types of providers, as diverse types of information are shared across and mutually benefit agencies. In the following quote, an advocacy coordinator from a nonprofit described the careful balance of providing accurate information while securing the image of other organizations:

“The biggest hurdle we have is convincing people that they have received the wrong information, and doing so in a manner that doesn’t malign or in any way dismiss the validity or good work of the organization they received that wrong information from.”

These additional types of work to create and maintain trust create challenges for non-governmental agencies in managing and providing information in a contextualized way.

Characteristics of Frequently Used Information Sources

The User Survey results support the importance of trust and relationship in information access. [Table 1](#) presents overall User Survey participants’ top 10 information sources. Survey participants were people with disabilities and their family members. The results are consistent with the Board’s 2022 Information Access Assessment in that people with disabilities and their family members are more likely to find information from informal information sources, such as family and friends. Also, the results show that non-governmental agencies are important information sources for people with disabilities and their family members, as non-governmental agencies put major efforts into building relationships.

Rank	Information Source	Classification	# of Respondents
1	Google (General Search)	Search Engine	182
2	Department of Medical Assistance Services	Government	132
3	Family Member	Personal Network	107
4	The Arc of Virginia	Non-Gov Agency	85
5	Friend	Personal Network	71
6	Moms in Motion	Non-Gov Agency	71
7	The Arc of Northern Virginia	Non-Gov Agency	68
8	Other Parents of Children or Adults with Disabilities/Special Needs	Personal Network	65
9	Primary Care Doctor	Medical Experts	63

Rank	Information Source	Classification	# of Respondents
10	Facebook	Social Media	60

Table 1. Top 10 Information Sources mentioned by the survey respondents overall.

[Appendix G](#) presents frequently used information sources by different demographic groups in detail. When it comes to people with *developmental disabilities*, the ranking of the information sources slightly changes. While popular information sources are similar, people with developmental disabilities and their family members tend to rely more on the Department of Medical Assistance Services (DMAS) and less on social media. The top 10 information sources for *people who are covered by Medicaid* are similar to the overall respondents as well. One difference is that people who are covered by Medicaid contact the Social Security Administration (SSA) as a major information source. The popular information sources for *people of color* and *those living in rural areas* are also similar to the overall respondents.

Meanwhile, *people whose household income is below the poverty line* (less than \$30,000) are more likely to rely more on their primary care doctors. Also, people below the poverty line use more diverse social media than other demographic groups. Specifically, they rely on Facebook and TikTok. Finally, the use of DMAS as an information source is less than that of other populations within the respondents.

Overall, our findings suggest that there is a need to help people with disabilities and their family members contact and use government information sources more easily by creating an inclusive and stigma-free atmosphere.

Recommendation 8: Support the Creation of a Stigma-Free Environment

The Department of Medical Assistance Services (DMAS), Department of Behavioral Health and Developmental Services (DBHDS), Department of Social Services (DSS) and Virginia Department of Health (VDH), in coordination with the stakeholder community, should collaboratively develop and implement strategies for creating a stigma-free atmosphere to mitigate information access issues.

- To combat the fear or stigma that people with disabilities and family members experience when asking for help from government agencies, state agencies should change people’s perception of “asking for help” to “having a right to use services.”
- State and local agencies can create informal protocols (or partnerships) that increase easy access by people with disabilities and their family members.

Recommendation 8: Support the Creation of a Stigma-Free Environment (Continued)

- DBHDS, DSS, VDH and CSBs can launch a campaign that rebrands their services as fundamental rights, rather than merely responses to requests for help. This initiative aims to promote proactive use of these services, encouraging individuals to view them as rightful entitlements.

Improve the Capacity of Government Information Sources while Providing an Easy Validation Method for Non-Governmental Information

User Survey respondents' levels of trust for the information provided by their preferred information sources were all high. However, many government-initiated web resources such as No Wrong Door or My Life My Community (Virginia Navigator), were rarely mentioned by the survey respondents. Given the fact that many people utilize informal information sources (e.g., family and friends) and general web searches (see [Appendix G](#)), recommendations are as follows.

Recommendation 9: Develop and Implement Strategies to Improve Capacity and Awareness of Information Services

The Department of Medical Assistance Services (DMAS), Department of Behavioral Health and Developmental Services (DBHDS) and Department of Social Services (DSS), in coordination with the government-initiated resources and initiatives, should collaboratively develop and implement strategies for improving the capacity and awareness of their information services (e.g., the number of frontline staff, promotion of existing information systems), because people of diverse backgrounds and regions heavily use government resources as their main information sources, while not being aware of certain government-sponsored websites (e.g., No Wrong Door).

- DBHDS, DMAS and DSS need to develop strategies to improve the capacity of their information services, such as increasing the number of frontline staff members and promoting government-initiated resources (e.g., examining people's awareness of and the usability of the systems).
- No Wrong Door and Virginia Navigator need to develop strategies to promote their resources to a broader community through outreach and public events.

Recommendation 10: Increase Monitoring of Information to Mitigate Misinformation or Conflicting Information

Because many people with disabilities and their family members acquire disability service information through Google searches, non-governmental agencies, websites and social media, the Department of Behavioral Health and Developmental Services (DBHDS) and the Department of Medical Assistance Services (DMAS) should take proactive action and increase the monitoring of information provided by these sources to mitigate misinformation or any conflicting information provided by different sources.

- **Increased Monitoring:** DBHDS and DMAS could create an information audit program (e.g., information staff member or automated information systems) to monitor different kinds of information provided to people with disabilities and their family members.
- **Proactive Actions:** DBHDS and DMAS can create information literacy programs (e.g., use cases, educational videos) to help information users navigate through different kinds of information outside of government information sources.

Appendix A: Interview Protocol

General Questions

1. What is your official job title? Could you briefly explain your role in your organization?
2. Could you explain what your agency/organization does with regards to disability services (or to support people with disabilities)?
3. Please describe your organization's typical consumer or clientele?
 - a. Geographical Boundaries: Is there a specific geographical region when serving consumers/clients?
 - b. IF NOT SERVING CONSUMERS DIRECTLY: Are you only working with/serving organizations that serve specific geographical regions? (e.g., the state-level agencies, national-level orgs, local orgs, or geo boundaries don't matter)
4. *[Optional]* Describe a typical day at work?
 - a. PROMPT: Does your typical workday involve helping consumers/clients find relevant disability services information?
 - b. If yes– please tell me about that?

Information Challenges When Delivering Services to Clients

1. *[Optional]* What kinds of challenges do you experience when delivering disability services to consumers/clients?
 - a. PROMPT: What about in cases specifically for Medicaid services?
 - b. PROMPT: What about when providing information to non-English speakers/readers?
2. What is the biggest hurdle faced when providing information about disability services (either their own or others') to consumers/clients?
 - a. PROMPT: What about in cases specifically for (or related to) Medicaid services about disabilities?
 - b. PROMPT: What about when providing information to non-English speakers/readers?
3. Are certain customer demographics (groups of consumers/clients) more difficult to reach out to than others?
 - a. PROMPT: Are there any differences between reaching consumers/clients who are parents/caregivers and who are people with I/DD (Intellectual/Developmental Disabilities) themselves?

Types of Information They Handle

1. What kinds of disability services information for consumers/clients do you manage or store in your organization?

- a. PROMPT: Do you have to provide “how-to” information to consumers/clients—for example, step-by-step instructions about how to access disability services to consumers/clients? If yes— tell me about that?
- b. PROMPT: Do you have to provide “what is?” meaning definitions and explanations to consumers/clients? If yes— tell me about that?
2. How do you maintain that information in your organization? (e.g., specialized databases, websites, shared drives, separate documents, job experience/memory, etc.)
 - a. PROMPT: What are normal practices to find specific information within your agency/org? (e.g., if there are lots of documents and one person doesn’t know where some docs are, what’s the approach?)

Current Way of Providing Information

1. How is disability services information distributed or provided to consumers/clients? (e.g., through phone calls, in-person visits, social media, (e-)mail/list servs, paper/electronic literature, etc.)
2. When you cannot provide required information, what’s your strategy or workaround?
 - a. PROMPT: For example, do you ask other people or agencies, or refer them to any other information sources?
3. What are your organization’s strategies or protocols to ensure disability services information is reaching the correct target customer population?
4. Are there any special permissions consumers/clients/users need to have to access the disability service information? (e.g., Medical Assistance ID, official referrals?)
5. Are there any ways, such as training programs, that help the support staff provide accurate (or trusted) information to consumers/clients?
 - a. PROMPT: If so, how do they look?
 - b. PROMPT: If not, what’s the on-the-job training (OJT) or onboarding process look like (for staff)?

Management + Flow of Information

1. How often is consumer/customer-facing disability information updated?
 - a. PROMPT: If they have previously mentioned they work with different kinds of information, make sure to ask about the different kinds because they may be updated at different intervals.
2. What is the update process when new disability information is available?
 - a. PROMPT: How do you know there’s new disability information?
 - b. PROMPT: How would you acquire or access the new disability information?
3. What external websites or agencies are useful for your disability service information management?
 - a. PROMPT: Who/what are they?

- b. PROMPT: How do you use external websites or agencies to help you manage your organization's disability services information?
 - c. PROMPT: How do you ensure the accuracy and credibility of this information? In other words, is there inaccurate or conflicting information? If so, how do you deal with it?
4. Do you refer consumers/clients to any external information sources to provide any Medicaid service information? If yes: What are these external information sources?
5. Do you refer consumers/clients to any internal information sources to provide any such information? If yes: What are these internal information sources?
6. Do you have any (either formal or informal) partnerships with other organizations or agencies to share disability services or service-related information?
 - a. If yes: Please describe them?
7. Does your organization share any disability information with other agencies (formally or informally)?
 - a. If yes:
 - i. Which agencies?
 - ii. How is the information shared?

Reflection

1. Do you have any “ideal” solution to better provide information– for example, if you had a magic wand, what would you create to fix your problems with providing information to consumers/clients?

Appendix B: Survey Protocol

The Provider Survey: Survey for Providers

In this survey, we ask about the kinds of disability-related information you provide and share with clients and other organizations. We aim to understand how providers share with, provide to, and use information from different information sources. Responses will remain anonymous.

Funding for this project/product was supported, in part, by the Virginia Board for People with Disabilities, under grant number 2301VASCDD, from the U.S. Administration for Community Living (ACL), Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.

1. What is the name of the agency or organization you work for? [Open-ended]
2. How many years of experience do you have in this field?
 - a. 0-5 years
 - b. 5-10 years
 - c. 10-20 years
 - d. 20+ years
3. Which of the following best describes the type of organization you work for?
 - a. State government agency
 - b. Local government agency
 - c. Private or Nonprofit provider
 - d. Advocacy organization
 - e. School/Education System
 - f. Other (please specify):
4. In Virginia, what cities or counties do your organization serve? Please check all that apply.
 - a. State-wide coverage
 - b. Specific cities/counties (please specify):

Providing Information

The following questions are all about disability-related information that you share with or provide to other people, websites, or organizations as part of your work.

5. To whom do you or your organization provide disability-related information? (Select all that apply.)
 - a. People with disabilities and family members

- b. Government agencies
- c. Non-government organizations

Providing Information to Individuals and Families

(Conditional to the answer to Q5, if “a” is checked)

6. What kind of information do you or your organization provide **to individuals with disabilities and their families?** (Select all that apply.)
 - a. How to apply for Medicaid
 - b. How to apply for Medicaid Waiver
 - c. How to apply for disability-related services other than Medicaid
 - d. How to use Technologies
 - e. Clarifications about policies and regulations
 - f. Contact information of other providers or support groups
 - g. Information about specific programs/services
 - h. Other (please specify):
7. How do you provide information to individuals with disabilities and families? (Select all that apply.)
 - a. E-mail
 - b. Phone call
 - c. In person
 - d. Websites
 - e. Mobile apps
 - f. Listserv or emailing list
 - g. Snail mail
 - h. Organization’s internal information system (e.g. sending a message through the organization’s online portal)
 - i. Other (please specify):
8. How often do you provide information to individuals with disabilities and families? (Select all that apply.)
 - a. Multiple times a day
 - b. Almost every day
 - c. Once or twice a week
 - d. Once or twice a month
 - e. Once or twice a year
 - f. Other (please specify):

Providing Information to Government and Non-governmental Organizations

(conditional to Q5, if “b” or “c” is checked)

9. Which organizations or websites do **you or your organization** provide information to? "Information" in this question includes, but is not limited to, disability services, policies, regulations, or events (but does not include discussions, paperwork, feedback, or information that's not directly related to disabilities).

Please write down the names of the **Top 5 organizations or websites** that receive information from you or your organization (minimum of 3 answers required).

- a. Open ended questions (5 fields)

[Q10-12 shows up multiple times, per each information source specified in Q19]

10. [Conditional to Q9] What kind of information do you provide to [each source specified in Q9]? (Select all that apply.)
- a. How to apply for Medicaid
 - b. How to apply for Medicaid Waiver
 - c. How to apply for disability-related services other than Medicaid
 - d. How to use Technologies
 - e. Clarifications about policies and regulations
 - f. Contact information of other providers or support groups
 - g. Information about specific programs/services
 - h. Other (please specify):
11. [Conditional to Q9] How do you provide information [each source specified in Q9]? (Select all that apply.)
- a. E-mail
 - b. Phone call
 - c. In person
 - d. Websites
 - e. Mobile apps
 - f. Listserv or emailing list
 - g. Snail mail
 - h. Organization's internal information system (e.g. sending a message through the organization's online portal)
 - i. Other (please specify):
12. [Conditional to Q9] How often do you provide information to [each source specified in Q9]? (Select all that apply.)
- a. Multiple times a day
 - b. Almost every day
 - c. Once or twice a week
 - d. Once or twice a month

- e. Once or twice a year
- f. Other (please specify):

Receiving / Seeking Information

13. Who or what are the **Top 5 information sources** you use as part of your work to seek or find disability-related information, outside of your organization (e.g., to look up new policies and/or regulations, to connect individuals and families to service providers)? Information sources could include state agencies, organizations, websites, social media or word-of-mouth.

For organizations, websites, or groups, please provide **their specific names or addresses** (e.g., findhelp.org, Virginia Disability Support Group on Facebook). For word-of-mouth, please provide **your relationship to them** (e.g., coworker from another agency). Provide at least three responses.

- a. [Open ended questions (5 fields)]

[Q14-18 shows up multiple times, per each information source specified in Q13]

14. [Conditional to Q13] What kind of information do you seek from [each source specified in Q13]? (Select all that apply.)
- a. How to apply for Medicaid
 - b. How to apply for Medicaid Waiver
 - c. How to apply for disability-related services other than Medicaid
 - d. How to use Technologies
 - e. Clarifications about policies and regulations
 - f. Contact information of other providers or support groups
 - g. Information about specific programs/services
 - h. Other (please specify):
15. [Conditional to Q13] Through which **channel** do you find or search for information from [each source specified in Q13]? (Select all that apply.)
- a. E-mail
 - b. Phone call
 - c. In person
 - d. Snail mail
 - e. Their websites
 - f. Mobile apps
 - g. Information systems (e.g., electronic transfer of information through internal/organizational workflow)
 - h. Other (please specify):

16. [Conditional to Q13] When you use or contact [each source specified in Q13], is your information seeking/finding process formal or informal?
- Formal communication (e.g., state or local government policies, based on MOU, organizational agreements, official email exchange, contracts, automatic system updates, etc.)
 - Informal communication (e.g., viewing websites, word-of-mouth, casual & individual email exchange, etc.)
 - Both formal and informal communication
 - Other (please specify):
17. [Conditional to Q13] How often do you seek or find information through/from [each source specified in Q9]? (Select all that apply.)
- Multiple times a day
 - Almost every day
 - Once or twice a week
 - Once or twice a month
 - Once or twice a year
 - Other (please specify):
18. [Conditional to Q13] How trustworthy is the information received from [each source specified in Q9]??
- Very trustworthy
 - Trustworthy
 - Neutral
 - Untrustworthy
 - Very untrustworthy

The User Survey: Survey for People with Disabilities or Their Family Members

This survey aims to understand the information sources people use for disability-related services, kinds of information they seek, and their trust level. Participants' responses will remain anonymous.

This survey is provided in six different languages: English, Spanish (Español), Arabic (العربية), Chinese (中文), Korean (한글), and Vietnamese (Tiếng Việt). Please select your preferred language from the dropdown menu on the top-right corner.

Funding for this project/product was supported, in part, by the Virginia Board for People with Disabilities, under grant number 2301VASCDD, from the U.S. Administration for Community Living (ACL), Department of Health and Human Services, Washington, D.C. 20201. Grantees

undertaking projects with government sponsorship are encouraged to express their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.

1. What is your relationship to the person with a disability? (Select all that apply.)
 - a. Self (person with disabilities)
 - b. Family member of a person with disabilities
 - c. Primary caretaker (non-family) for a person with disabilities
 - d. Prefer to self-describe: _____
2. Are you a resident in the State of Virginia?
 - a. Yes, I mainly stay in Virginia
 - b. No, I mainly stay outside of Virginia
3. [if "a" is not selected from Q1] Is the person with disabilities you care for a resident in the State of Virginia?
 - a. Yes, the person with disabilities mainly stays in Virginia
 - b. No, I mainly stay outside of Virginia
4. What type of disability do you or your family/friend have? (Select all that apply.)
 - a. Developmental (e.g., intellectual disability, autism, cerebral palsy)
 - b. Cognitive (e.g., dyslexia, learning difficulties, speech disorders)
 - c. Physical (e.g., mobility impairment, Arthritis, etc.)
 - d. Sensory (e.g., hearing impairment, vision impairment, etc.)
 - e. Psychological (e.g., personality disorders, Schizophrenia, etc.)
 - f. Prefer to self-describe: _____
5. Which of the following best describes where you live? Your answer is anonymous. Your city or county is considered urban if at least 50% of its population lives in an urban area defined by the Census Bureau. For data on your city or county, see Column M in the U.S. Census Bureau's "County-Level 2020 Census Urban and Rural Information" table.
 - a. Rural
 - b. Urban
 - c. I do not know
 - d. I do not want to answer
6. Describe the insurance coverage for the person with disabilities.
 - a. Uninsured
 - b. Medicaid
 - c. Medicare
 - d. Private or Employment-based
 - e. Other (please specify):
7. How well do you speak or understand English?

- a. Very Well
 - b. Well
 - c. Not Well
 - d. Not at all
8. Do you have internet access at your home?
- a. Yes
 - b. Yes, but very limited
 - c. No
9. Are you able to use a computer or mobile device to find information on the internet?
- a. Yes
 - b. Yes, but very limited
 - c. No
10. Who or what are the Top 5 information sources you rely on for finding/seeking information about disability-related services? These can include organizations (e.g., Virginia Department of Medical Assistance Services), advocacy organizations (e.g., The Arc of Virginia), social media (e.g., a Facebook group called "ABC"), or individuals (e.g., trusted contact or close friends who are nurses).

For organizations, websites, or groups, please provide their specific names or addresses (e.g., findhelp.org, Virginia Disability Support Group on Facebook).

For specific individuals, please provide your relationship to them (e.g., friend, neighbor, coworker).

Provide at least three responses.

- a. Open ended questions (5 fields)

[Q11-14 shows up multiple times, per each information source specified in Q10]

11. [conditional to Q10] What kind of information do you seek from [Each answer of Q10]? (Select all that apply.)
- a. How to apply for Medicaid
 - b. How to apply for Medicaid Waiver
 - c. How to apply for disability-related services other than Medicaid
 - d. How to use Technologies
 - e. Clarifications about policies and regulations
 - f. Contact information of other providers or support groups
 - g. Information about specific programs/services
 - h. Other (please specify):

12. [conditional to Q10] How do you access information from [Each answer of Q10]? (Select all that apply.)
- a. E-mail
 - b. Phone call
 - c. In person
 - d. Snail mail
 - e. Their websites
 - f. Mobile apps
 - g. Other (please specify):
13. [conditional to Q10] How often do you use or contact [Each answer of Q10]?
- a. Multiple times a day
 - b. Almost every day
 - c. Once or twice a week
 - d. Once or twice a month
 - e. Once or twice a year
 - f. Other (please specify):
14. [conditional to Q10] How trustworthy is the information received [Each answer of Q10]?
- a. Very trustworthy
 - b. Trustworthy
 - c. Neutral
 - d. Untrustworthy
 - e. Very untrustworthy

[Matrix style: rows of the specified info sources and columns of trust levels, 5-Likert scale]

15. Generally speaking, how trustworthy is information received from each information source?
- a. State offices (e.g., DMAS/Medicaid, Department of Behavioral Health & Developmental Disabilities)
 - b. County offices (e.g., Community Services Board (CSB), County Social Services office, or County/City Health Department)
 - c. Advocacy organizations (e.g., The Arc of Virginia)
 - d. Doctors or medical clinics
 - e. Education system or school-based resources (e.g., Parent Resource Center, School Transition Coordinator)
 - f. Self-advocate Support Organizations or Disability-based Associations (e.g., ALLY Alliance, Center for Family Involvement, Autism Associations, Down Syn. Society)
 - g. Center for Independent Living (e.g., ENDependence Center and Access Independence)

- h. Your own family members and close friends
 - i. Other families or informal family groups who have similar experiences
 - j. No Wrong Door / Virginia Easy Access
 - i. Facebook
 - ii. X (Twitter)
 - iii. Instagram
 - iv. Reddit
 - v. findhelp.org
 - vi. Google (open-ended search)
16. What is the name of your primary city or county of residence in Virginia?
- a. Open-ended
17. Please select your gender.
- a. Female
 - b. Male
 - c. Nonbinary
 - d. I do not want to answer
 - e. Prefer to self-describe: _____
18. What is your age?
- a. 18-24
 - b. 25-34
 - c. 35-44
 - d. 45-54
 - e. 55-64
 - f. 65 and over
 - g. Prefer not to answer
19. Which of the following best describes your race and ethnicity? (Select all that apply.)
- a. American Indian or Alaska Native
 - b. Asian
 - c. Black or African American
 - d. Hispanic/Latinx
 - e. Native Hawaiian or Other Pacific Islander
 - f. White
 - g. Other race or ethnicity
 - h. I do not know
 - i. I do not want to answer
 - j. Prefer to self-describe: _____
20. What is your total household income annually?
- a. Less than \$30,000

- b. \$30,000 to less than \$50,000
- c. \$50,000 to less than \$70,000
- d. \$70,000 to less than \$90,000
- e. \$90,000 to less than \$110,000
- f. \$110,000+

Appendix C: Interviewee Demographics

State

Serving the Entire State of Virginia

Organization	Interviewees	Management Areas	Participant Roles
Department of Behavioral Health and Developmental Services	9	Program Management, Waiver Support, Individual Support, Provider Support	High-level, Mid-level, Frontline
Department for Aging and Rehabilitative Services	4	Program Management, Community Outreach, Individual Support, Provider Support	High-level, Mid-level, Frontline
Department of Medical Assistance Services	3	Program Management, Service Quality Oversight	High-level, Mid-level
Virginia Department for the Deaf and Hard of Hearing	2	Strategy Planning, Individual Support	High-level, Mid-level/ Frontline
Department for the Blind and Vision Impaired	1	Program Management	High-level/ Mid-level

Table C1. State agency interviewee demographics.

Local

Serving 9 Regions in Virginia

Organization	Interviewees	Management Areas	Participant Roles
Fairfax-Falls Church Community Services Board	11	Strategy Planning, Program Management, Individual Support	High-level, Mid-level, Low-level, Frontline
Chesterfield Community Services Board	2	Strategy Planning, Program Management	High-level, Mid-level

Organization	Interviewees	Management Areas	Participant Roles
Danville-Pittsylvania Community Service Board	1	Strategy Planning, Program Management	High-level
Henrico Area Community Services Board	1	Strategy Planning, Program Management	High-level
Mount Rogers Community Services Board	1	Strategy Planning, Program Management	High-level
Rappahannock Rapidan Community Services Board	1	Strategy Planning, Program Management	High-level

Table C2. Local agency interviewee demographics.

Nonprofit/For-Profit

Serving the Entire State and/or Specific Regions in Virginia

Organization	Interviewees	Management Areas	Participant Roles
Deaf and Hard of Hearing Services Center	3	Individual Support	Low-level, Frontline
Access Independence, Winchester	2	Strategy Planning, Program Management, Individual Support	High-level, Low-level, Frontline
Rehabilitative Services and Vocational Placement, Inc.	2	Employment Support	Low/Frontline Mid-level/ Frontline
SOAR365	2	Support Oversight / Strategy Planning Case Management	High-level
Virginia Association of Centers for Independent Living	2	Support Oversight / Strategy Planning	Mid-level/ Frontline
Virginia Commonwealth University Partnership for People with Disabilities	2	Support Oversight / Strategy Planning	High-level

Organization	Interviewees	Management Areas	Participant Roles
Autism Society of Central Virginia	1	Support Oversight / Strategy Planning	High-level,
disAbility Resource Center	1	Community Support	Mid-level/ Frontline
New River Valley Disability Resource Center	1	Support Oversight / Strategy Planning	High-level
Northstar	1	Support Oversight / Strategy Planning	High-level
Spectrum Transformation Group	1	Support Oversight / Strategy Planning	High-level
The Arc of Virginia	1	Information Management	High-level
The Choice Group	1	Operations Management	High-level
The disAbility Resource Center of the Rappahannock Area, Inc.	1	Community Support	Mid-level/ Frontline
The Faison Center	1	Research Oversight	High-level
VCU Autism Center for Education	1	Disability Specialist	Mid-level/ Frontline
Virginia Association for Behavior Analysis	1	Consultant	Mid-level/ Frontline
Virginia Navigator	1	Support Oversight / Strategy Planning	High-level

Table C3. Nonprofit and for-profit organization interviewee demographics.

Appendix D: Demographic and Organizational Characteristics of Survey Respondents

Category	Sample Composition
User Language for Survey	English (876), Spanish (7), Korean (3), Vietnamese (1)
Urban/Rural Region	Urban (506), Rural (320), Others (61)
Types of Disabilities (multiple answers possible)	Developmental (550), Physical (336), Cognitive (277), Psychological (196), Sensory (141)
Types of Insurance (multiple answers possible)	Medicaid (567), Private or Employment-based (332), Medicare (238), Uninsured (18)
English Proficiency	Very well (845), Well (35), Not well (7)
Internet Access at Home	Yes (843), Yes but Very Limited (38), No (6)
Digital Literacy (being able to access information using the Internet and technology)	Yes (844), Yes but Very Limited (38), No (5)
Home County/City	Top 10 counties in terms of survey responses: Fairfax (85), Virginia Beach (36), Chesterfield (36), Richmond (35), Norfolk (30), Henrico (29), Roanoke (25), Stafford (19), Newport News (19), Loudoun (18)
Gender	Female (680), Male (179), Non-binary (10), Others (18)
Age Groups	18-24 (47) 25-34 (99) 35-44 (226) 45-54 (227) 55-64 (157) 65 and over (112) Prefer not to answer (19)
Ethnicity (multiple answers possible)	White (605), Black or African American (169), Hispanic/Latino/a (55), Asian (43), American Indian or Alaska Native (21), Native Hawaiian or Other Pacific Islander (5), Other race or ethnicity (18)

Category	Sample Composition
Income Range	\$110,000+ (188) \$90,000 to less than \$110,000 (78) \$70,000 to less than \$90,000 (89) \$50,000 to less than \$70,000 (120) \$30,000 to less than \$50,000 (147) Less than \$30,000 (174) Prefer not to answer (91)

Table D1. Demographic information of the User Survey respondents.

Category	Sample Composition
User Language for Survey	English (95)
Years of Experience in the Field	0-5 years (16) 5-10 years (13) 10-20 years (36) 20+ years (30)
Types of Organization	State government agency (7) Local government agency (14) Private or Nonprofit provider (74)
Served County/City	State-wide coverage (24) Specific counties/cities (71)
Providing Information To...	People with disabilities and family members (95) Government agencies (41) Non-government organizations (39)

Table D2. Respondents' characteristics for the Provider Survey.

Appendix E: Providers' Information Networks

The information sharing network between providers has been constructed based on the Provider Survey responses (see [Figure E1](#)). The blue dots represent information providers (agencies and organizations). The arrow represents “providing information.” Based on the arrows between agencies, it is possible to see how disability-related information flows across the agencies in the information ecology of disability services.

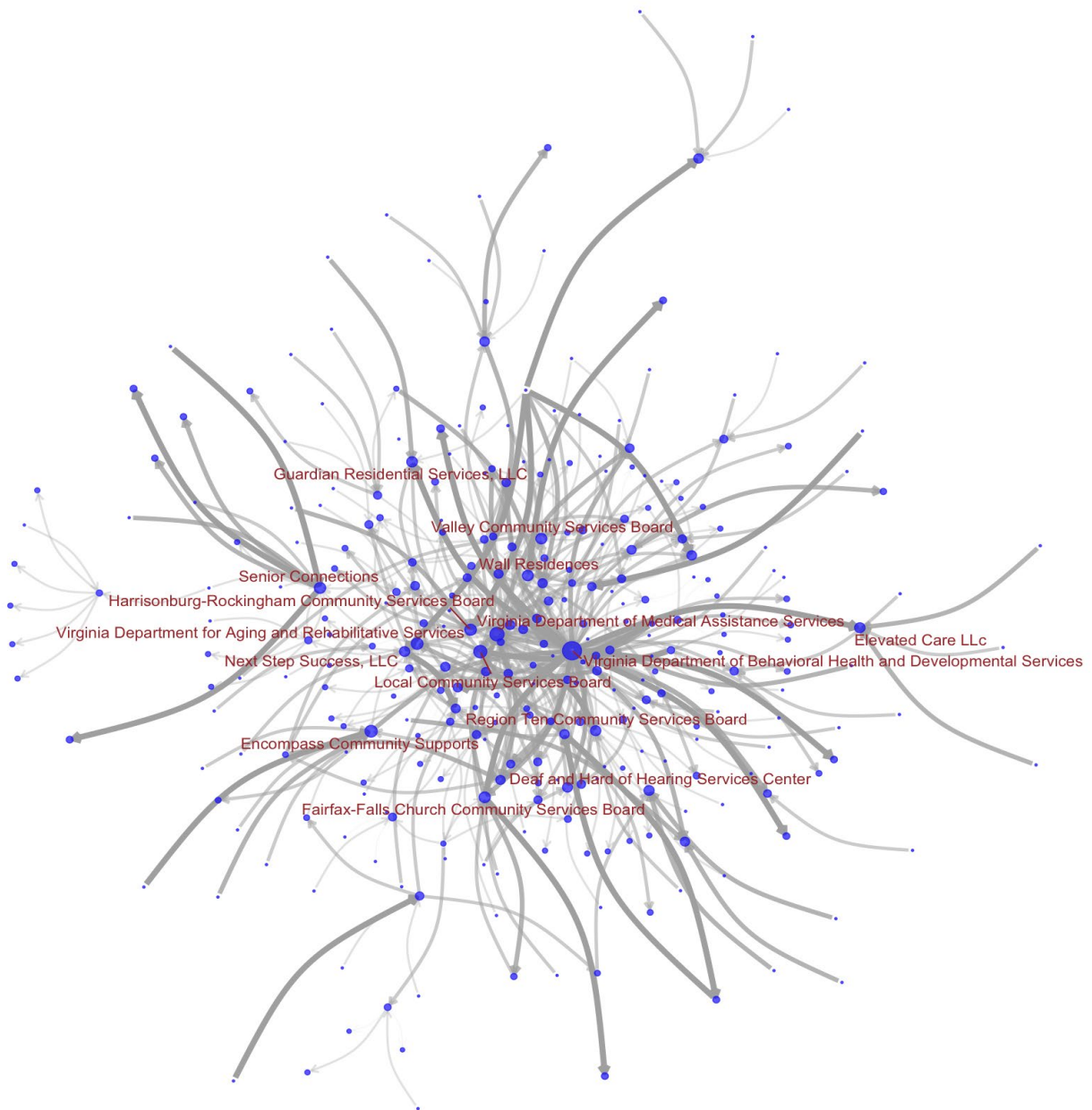


Figure E1. Networks of information sharing/provision between organizations (all kinds of information). The blue dots represent information providers (agencies and organizations). Arrows represent “providing information.”

Using the networks, [Table E1](#) reports top 10 agencies or websites in terms of their bridging, sourcing and seeking roles. These roles are measured using network measures, namely, *betweenness centrality*, *out-degree centrality* and *in-degree centrality* (Borgatti, 2005).

- **Bridging Role:** How much an agency (or information source) plays a role as a bridge between other information sources in sharing and disseminating disability services information. This is measured using *betweenness centrality*.
- **Sourcing Role:** How much an agency (or information source) plays a role as a major information source or provider for peer agencies and other providers. This is measured using *out-degree centrality*.
- **Seeking Role:** How much an agency (or information source) plays a role as a major information seeker or recipient who gathers information from peer agencies and providers. This is measured using *in-degree centrality*.

Rank	Bridging	Sourcing/Providing	Seeking/Receiving
1	Virginia Department of Behavioral Health and Developmental Services	Virginia Department of Behavioral Health and Developmental Services	Virginia Department of Behavioral Health and Developmental Services
2	Virginia Department of Medical Assistance Services	Virginia Department of Medical Assistance Services	Virginia Department of Medical Assistance Services
3	Harrisonburg-Rockingham Community Services Board	The Arc of Virginia	Harrisonburg-Rockingham Community Services Board
4	Encompass Community Supports	Local Community Services Board	Local Community Services Board
5	TrustPoint Residential Services	Virginia Network of Private Providers	Wall Residences
6	Virginia Department for Aging and Rehabilitative Services	My Life My Community	Virginia Department for Aging and Rehabilitative Services
7	Wall Residences	Harrisonburg-Rockingham Community Services Board	Encompass Community Supports
8	Volunteers of America Chesapeake and Carolinas	Wall Residences	Valley Community Services Board

Rank	Bridging	Sourcing/Providing	Seeking/Receiving
9	Social Security Administration	Google	Senior Connections
10	ENDependence Center of Northern Virginia (ECNV)	Social Security Administration	Fairfax-Falls Church Community Services Board

Table E1. Top 10 information sources in terms of their roles (all kinds of disability-related information).

The rankings show that while there are non-governmental agencies and websites that play key roles in the information ecology of disability services, state agencies, such as the Department of Medical Assistance Services (DMAS) and the Department of Behavioral Health and Developmental Services (DBHDS), and local Community Services Boards (CSBs) are key players in maintaining, gathering and providing information to other agencies and websites. Also, advocacy agencies, such as the Arc of Virginia, are highly ranked in terms of providing information to other agencies.

[Table E2](#) presents the similar rankings of the providers but focuses only on Medicaid-related information. While DMAS and DBHDS still play critical roles in the information ecology, one of the major differences is that when it comes to Medicaid information (e.g., Medicaid waiver), there are many non-governmental agencies who play important roles compared to other types of information. For example, Wall Residences, a private organization in Virginia, plays a key role in finding and receiving Medicaid-related information from other agencies, which potentially indicates that they might serve a broader population on behalf of other agencies. Also, Next Step Success, LLC, ranked number two in a bridging role, which indicates that they transfer, mediate or interpret Medicaid-related information very actively between different agencies.

Rank	Bridging	Sourcing/Providing	Seeking/Receiving
1	Virginia Department of Behavioral Health and Developmental Services	Virginia Department of Behavioral Health and Developmental Services	Wall Residences
2	Next Step Success, LLC	Virginia Department of Medical Assistance Services	Encompass Community Supports
3	Virginia Department of Medical Assistance Services	Eggleston	Virginia Department of Behavioral Health and Developmental Services
4	The Arc of Virginia	Community Services Board Hanover County	St. Joseph's Villa

Rank	Bridging	Sourcing/Providing	Seeking/Receiving
5	Local Community Services Board	Next Step Success, LLC	Guardian Residential Services, LLC
6	Eggleston	Local Community Services Board	Virginia Department of Medical Assistance Services
7	Social Services	Care Connection for Children, Children's Hospital of The King's Daughters	Local Community Services Board
8	Apex Day Support Services, LLC.	Virginia Department of Social Services	Dennis R. Brown LLC
9	Wall Residences	Medicaid	Elevated Care LLC
10	Virginia Department of Social Services	SSVA	Counseling and Advocacy Associates

Table E2. Top 10 information sources in terms of providers' roles, with a focus on Medicaid information.

Appendix F: Implications for Assessing the Fragmentation of Information

The network analysis provides a useful way to understand disability information at the ecological level. In particular, using network-based measures may help with assessing and monitoring the degree of information fragmentation at the state level. If disability service providers share information with each other, their connections with other providers through arrows will be dense within the network, and as a result, there will be more “cycles” created among the providers in the network. Conversely, if information is not shared effectively across the agencies, the number of arrows will be smaller, and the number of cycles in the network will also be small. These tendencies are measured using *cluster coefficients* (Fagiolo, 2007), which quantify the degree to which nodes in a network relate to each other. Specifically, there are five types of connectedness measurements: (1) cycle-based (when connections are circular), (2) bridging-based (when a provider plays a role as a bridge between other providers), (3) sourcing-based (when a provider becomes a main information source for others), (4) receiving-based (when a provider is a main information receiver from others), and (5) the total of the other four (i.e., overall connectedness). To illustrate the potential of assessing the fragmentation rates, [Table F1](#) provide the five types of network-level measures that quantify the degree of connectedness (Fagiolo, 2007; Wasserman & Faust, 1994).

	Cycle	Bridging	Sourcing	Receiving	Total
All Kinds of Information	0.006	0.009	0.017	0.008	0.019
Medicaid-Related Information Only	0.001	0.002	0.015	0.003	0.016

Table F1. Connectedness of information providers in Virginia.

The table shows that disability service providers relate to each other to some degree, regarding all kinds of disability-related information. When it comes to Medicaid-related information only, providers are less connected with each other, about 15% looser than that of the entire information ecology.

While these numbers do not have absolute meanings as they are, they can be used to compare and monitor the status of information fragmentation (1) across different types of information and (2) over time. If the numbers increase over time, for example, it indicates that information sharing increases across the providers in Virginia, which might be a result of certain interventions at the state level. Conversely, if any of the numbers decrease over time, the information ecology networks will be a basis for examining the locations of issues or the bottlenecks in disseminating information across the agencies, so that policymakers and information managers can develop informed strategies.

Appendix G: Frequently Used Information Sources by Demographic Groups

When it comes to people with developmental disabilities, the ranking of the information sources slightly changes compared to the overall rankings (see [Table 1](#) for the rankings for all types of information). While popular information sources are similar, *people with developmental disabilities* and their family members tend to rely more on the Department of Medical Assistance Services (DMAS) and less on social media (see [Table G1](#)).

Rank	Information Source	Classification	# of Respondents
1	Virginia Department of Medical Assistance Services	Government	98
2	The Arc of Virginia	Non-Gov Agency	81
3	Google	Search Engine	78
4	Moms in Motion	Non-Gov Agency	69
5	The Arc of Northern Virginia	Non-Gov Agency	68
6	Other parents of children (or adults) with disabilities/special needs	Personal Network	65
7	Virginia Department of Behavioral Health and Developmental Services	Government	54
8	Family member	Personal Network	31
9	Friend	Personal Network	31
10	Parent Educational Advocacy Training Center (PEATC)	Non-Gov Agency	24

Table G1. Top 10 information sources mentioned by the survey respondents who have developmental disabilities or are their family members.

The rankings of information sources *used by people who are covered by Medicaid* are presented in [Table G2](#). The popular information sources are similar to that of [Table 1](#). One difference is that they often contact the Social Security Administration (SSA) as a major information source.

Rank	Information Source	Classification	# of Respondents
1	Google	Search Engine	104
2	Virginia Department of Medical Assistance Services	Government	103

Rank	Information Source	Classification	# of Respondents
3	Moms in Motion	Non-Gov Agency	69
4	The Arc of Virginia	Non-Gov Agency	63
5	Family member	Personal Network	58
6	Other parents of children (or adults) with disabilities/ special needs	Personal Network	48
7	The Arc of Northern Virginia	Non-Gov Agency	47
8	Friend	Personal Network	42
9	Social Security Administration	Government	35
10	Virginia Department of Behavioral Health and Developmental Services	Government	35

Table G2. Top 10 information sources mentioned by the survey respondents who are covered by Medicaid.

The rankings of information sources used by *people of color* (i.e., non-white) are presented in [Table G3](#). The popular information sources are similar to those from [Table 1](#).

Rank	Information Source	Classification	# of Respondents
1	Google	Search Engine	181
2	Virginia Department of Medical Assistance Services	Government	129
3	Family member	Personal Network	101
4	The Arc of Virginia	Non-Gov Agency	85
5	Friend	Personal Network	71
6	Moms in Motion	Non-Gov Agency	71
7	The Arc of Northern Virginia	Non-Gov Agency	68
8	Other parents of children (or adults) with disabilities/special needs	Personal Network	65
9	Primary care doctor	Medical Experts	62
10	Facebook	Social Media	60

Table G3. Top 10 information sources mentioned by the survey respondents who are people of color (non-white).

The rankings of information sources used by *people who live in rural areas* are presented in [Table G4](#). The popular information sources are similar to those from [Table 1](#), while “WebMD” emerges as an important information source.

Rank	Information Source	Classification	# of Respondents
1	Google	Search Engine	77
2	Virginia Department of Medical Assistance Services	Government	48
3	Family member	Personal Network	39
4	Friend	Personal Network	32
5	The Arc of Virginia	Non-Gov Agency	32
6	Moms in Motion	Non-Gov Agency	30
7	Primary care doctor	Medical Expert	29
8	Facebook	Social Media	24
9	Social Security Administration	Government	20
10	WebMD	Website	19

Table G4. Top 10 information sources mentioned by the survey respondents who live in rural areas.

The rankings of information sources used by *people whose household income is below the poverty line* (less than \$30,000) are presented in [Table G5](#). The rankings are quite different from those of other demographic groups. The role of primary care doctors is critical among this population; also, their use of social media is more diverse than other demographic groups (e.g., TikTok). Finally, their use of DMAS as the information source is less than other populations among the respondents.

Rank	Information Source	Classification	# of Respondents
1	Google	Search Engine	29
2	Primary care doctor	Medical Expert	13
3	Social Security Administration	Government	12
4	Family member	Personal Network	10
5	Virginia Department of Medical Assistance Services	Government	10
6	Friend	Non-Gov Agency	9

Rank	Information Source	Classification	# of Respondents
7	Facebook	Social Media	6
8	WebMD	Website	6
9	TikTok	Social Media	5
10	Virginia Department of Behavioral Health and Developmental Services	Government	5

Table G5. Top 10 information sources mentioned by the survey respondents whose household income is below the poverty line.

Works Cited

- Borgatti, S. P. (2005). Centrality and network flow. *Social Networks*, 27(1), 55-71.
- Borgatti, S. P. (2003). Identifying sets of key players in a network. In *IEMC'03 Proceedings. Managing Technologically Driven Organizations: The Human Side of Innovation and Change*. 127-131. IEEE.
- Brandes, U. (2005). Network analysis: Methodological foundations (Vol. 3418). *Springer Science & Business Media*.
- England, P. (2005). Emerging theories of care work. *Annual Review of Sociology*, 31(1), 381-399.
- Fagiolo, G. (2007). Clustering in complex directed networks. *Physical Review E*, 76(2).
- Freeman, L. C. (1978). Centrality in social networks conceptual clarification. *Social Networks*, 1(3), 215-239.
- Lee, M., & Butler, B. S. (2019). How are information deserts created? A theory of local information landscapes. *Journal of the Association for Information Science and Technology*, 70(2), 101-116.
- Nardi, B. A., & O'Day, V. (2000). *Information ecologies: Using technology with heart*. MIT Press.
- Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research in Psychology*, 11(1), 25-41.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research*. Sage publications.
- Tavory, I., & Timmermans, S. (2014). *Abductive analysis: Theorizing qualitative research*. University of Chicago Press.
- Wasserman, S., & Faust, K. (1994). *Social network analysis: Methods and applications*. Cambridge University Press.



**Ratcliffe Building
1602 Rolling Hills Drive, Suite 100
Henrico, VA 23229
804-786-0016
info@vbpd.virginia.gov

www.vbpd.virginia.gov**