Mapping Information Ecology:
Understanding the Fragmentation of Disability Service Information

Myeong Lee

VBPD Webinar on Information Ecology

Virginia Board for People with Disabilities

cil. Community Informatics Lab

GM GEORGE MASON UNIVERSITY.

Allison Coles-Johnson

- Bachelor of Science in Nursing

- Master of Business Administration

- Retired Registered Nurse (RN) Manager

- Founded Greater Richmond Autism Coalition for Equality (GRACE), Commonwealth Autism

- Member of Virginia Board for People with Disabilities

Virginia's DD Council

Virginia Board for People with Disabilities

Authorized under the federal Developmental Disabilities (DD) Assistance and Bill of Rights Act.

Guided by federal State Plan Priorities.
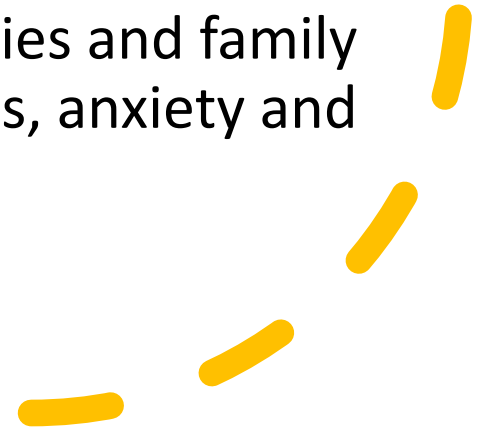
Why Information Ecology?

For many years, Virginians with I/DD and their families reported difficulty finding, understanding and using information on community services and supports that would help them live the lives they want.

These challenges are compounded by the complexity of the service delivery system and the fragmentation of sources of information.
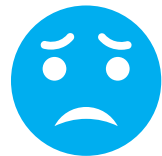
As a result, people with disabilities and family members report increased stress, anxiety and frustration.

Why Information Ecology?

The Virginia Board committed to tackling this hard, complex and systemic issue.

It was difficult to know where to start! There are a lot of unknowns and multiple layers to peel back.

Human Centered Design

What is Human Centered Design?

A problem-solving framework that helps make systems and products more responsive to the people who use those systems and products.

Understanding *what is the desired experience?*

Human Centered Design: 3 Phases

Inspiration

Learn from your customers.

Requires empathy.

Ideation

Brainstorm as much as possible. There are no bad ideas.

Implementation

Develop and test innovative solutions.

Phase 1: Inspiration

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

Contracted with Mary Lou Bourne,
Management Support Solutions Inc.

Assessment of Virginia's
Disability Services System:

Access to Information
for People with Disabilities
and their Family Members

Virginia Board for
People with Disabilities
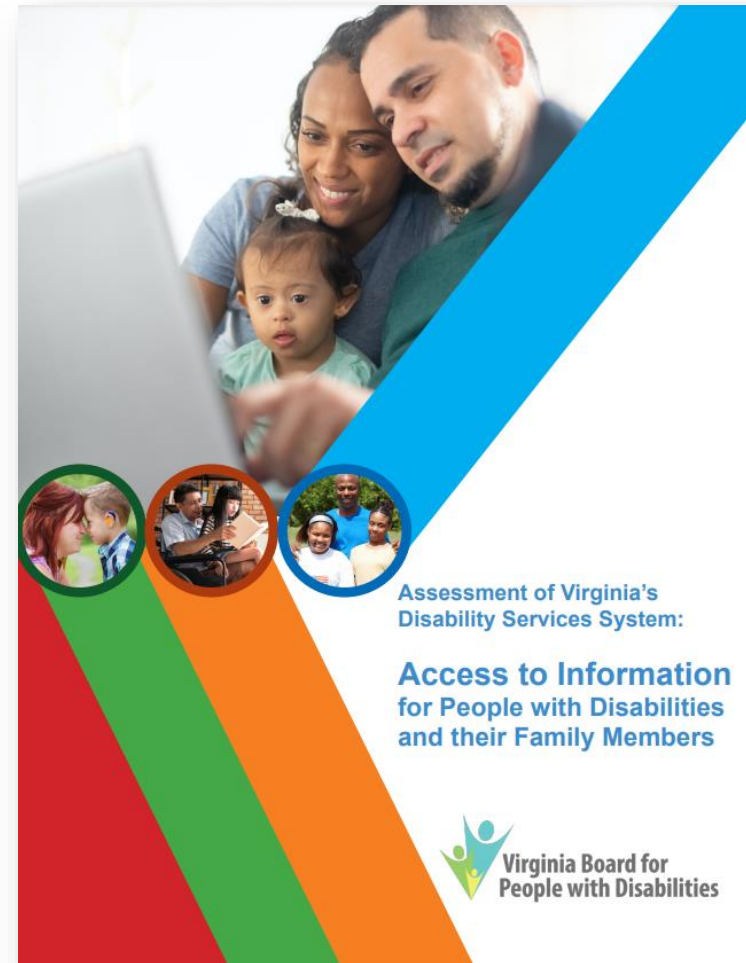
Common Statements from Focus Groups:

- People don't know where to start

- You must know the exact words to use, or you get shut out

- Information in too many different places and contradictory

- Overload of technical, legal information

Phase 2: Ideation

- Address systemic barriers impacting access to disability info that's
  - Reliable
  - Usable

- Act as a driving force for

  - Culture change
  - Enhanced customer service
  - Improved availability of reliable information

- Share stories

Phase 3: Implementation

What is an Information Access Champion?

A champion is an agency or organization that pledges to make its information as inclusive and accessible as possible. They agree to evaluate and improve their information accessibility in collaboration with the disability community.
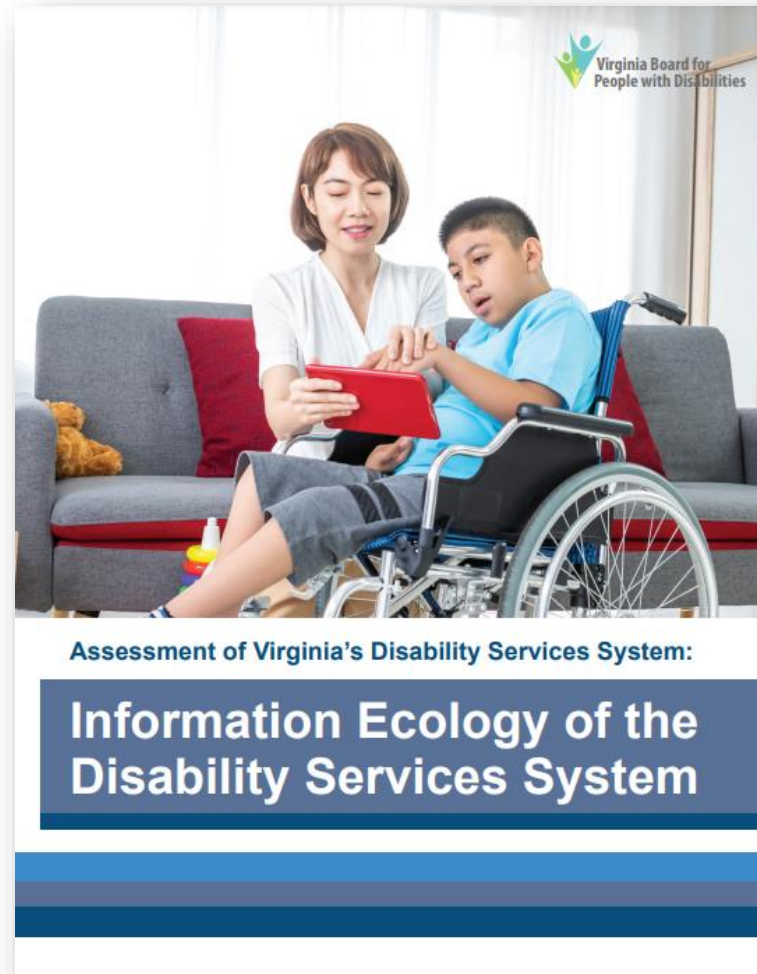
A champion is not perfect. But they are always trying. They improve information access by following info access values.

Phase 1: Inspiration

Assessment of Virginia's Disability Services System:

Information Ecology of the Disability Services System

Virginia Board for People with Disabilities

Dr. Myeong Lee

- Assistant Professor of Information Science and the Director of Community Informatics Lab, George Mason University

- Ph.D. in Information Studies

- Master of Information Management

- Master of Science in Software Engineering

- Bachelor of Science in Electrical Engineering

Reminder of My Story from 2022...
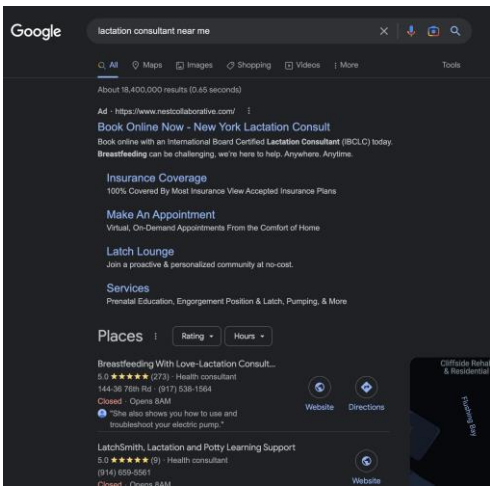
Preemie Baby
Born in
September 2022

She's happy
now!

We Desperately Needed to Find a Lactation Consultant (= breastfeeding expert).
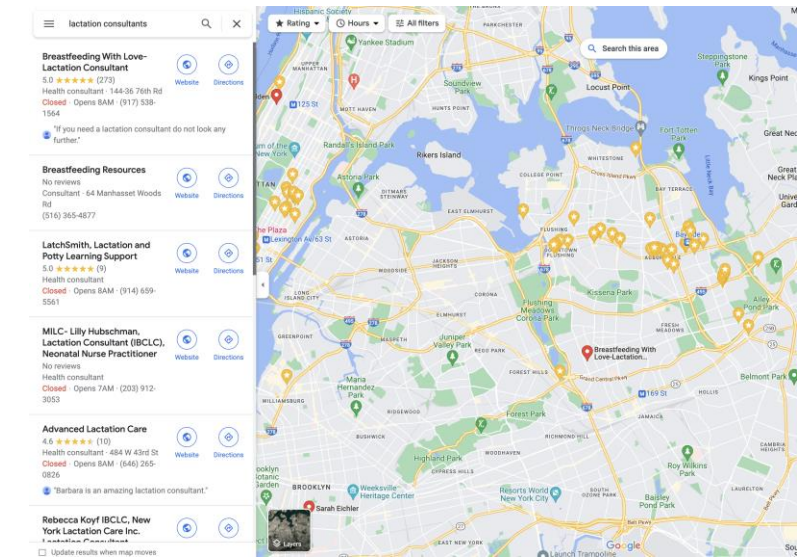
First,
I Googled

Third,
I Googled
on Maps

Second,
I Called My Insurance

Fourth,
I Called a
Children's
Hospital Near
Me

17

They Gave Me a Number

Her Schedule was Full

"Do you by chance know anybody who's nearby?"

Fourth,

I Called a Children's Hospital Near Me

They Don't Provide Outpatient Services

Before Hanging Up, I Asked: "Do you by chance know anybody who's nearby?"

They Gave Me a Number

Her Schedule was Full

"Do you by chance know anybody who's nearby?"

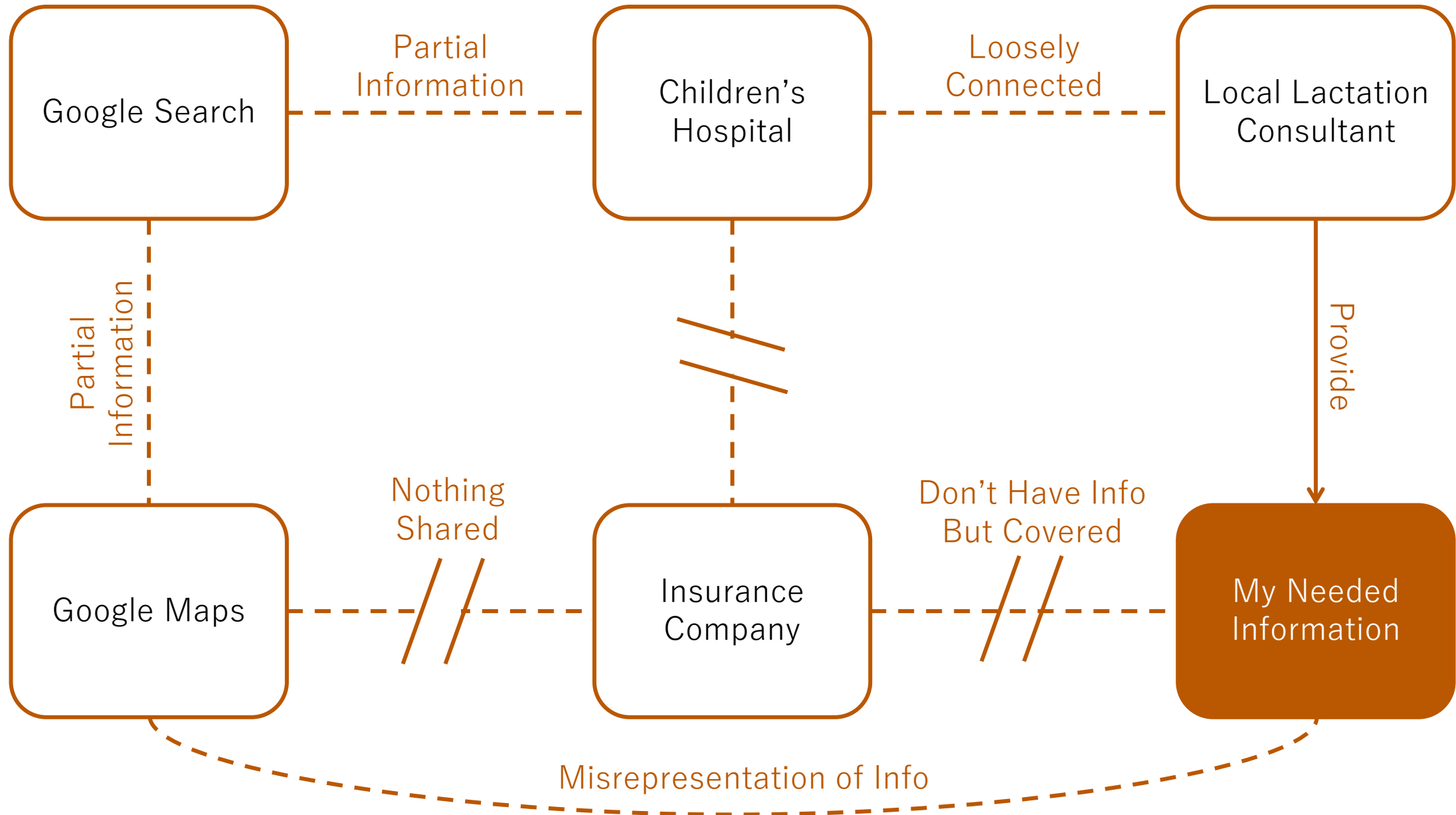This person was listed as "**Pediatrician**" on Google Maps

Before Hanging Up, I Asked: "Do you by chance know anybody who's nearby?"

Fourth,

I Called a Children's Hospital Near Me

They Don't Provide Outpatient Services

Information Ecology of Lactation Consultants

20

Information Ecology of Lactation Consultants

Google Search — Partial Information — Children's Hospital — Loosely Connected — Local Lactation Consultant

Partial Information

Nothing Shared

Had to ACTIVELY ASK to acquire info

Provide

Don't Have Info But Covered

Google Maps — Insurance Company — My Needed Information

Misrepresentation of Info

Information Ecology:

An arrangement of information sources, users, providers and how they relate to each other

Google Search

Hospitals and Clinics

Local Community Groups

How can We Make the <u>Information Ecology of Disability Services</u> Easier to Navigate?

Standalone Websites

Insurance Company

Governments

By Understanding:

1. Providers' Management of Information
2. Ecological Issues in Disability Information

The Goal of the Project

Understanding Disability Service Providers' Challenges

Understanding the Ecological Issues in Virginia's Disability Information

Then,

It becomes possible to think about state-wide and system-wide solutions

What We Did

Interviews w/ Providers
(State, Local, and Private)

To understand providers' challenges in providing disability information

Surveys for both Providers and Users
(95 providers; 886 users)

To identify key information sources communicated

Network Analysis of Information Sources

To understand the ecological issues in the disability information

What We Did

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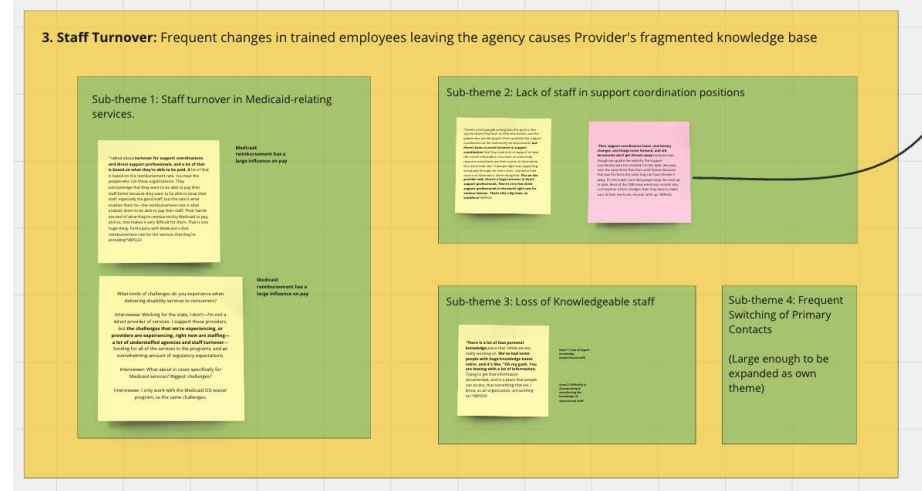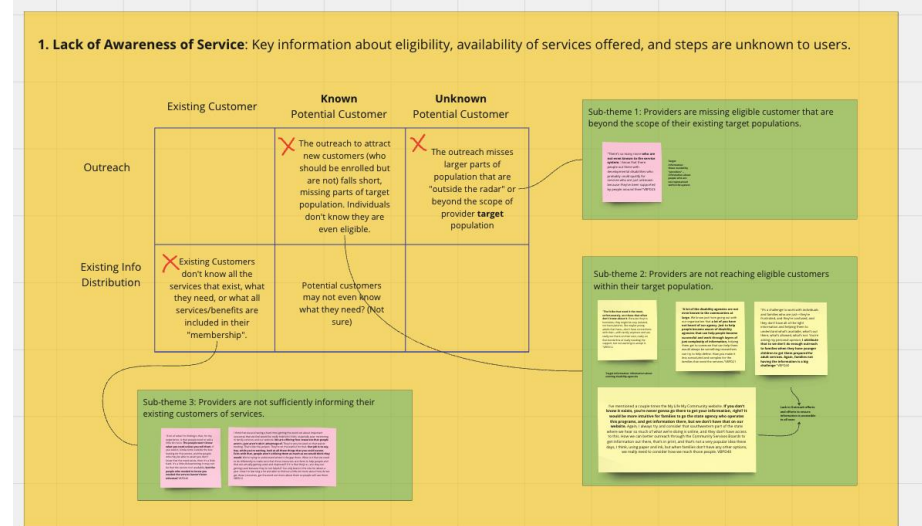To identify key information sources communicated

Network Analysis of Information Sources

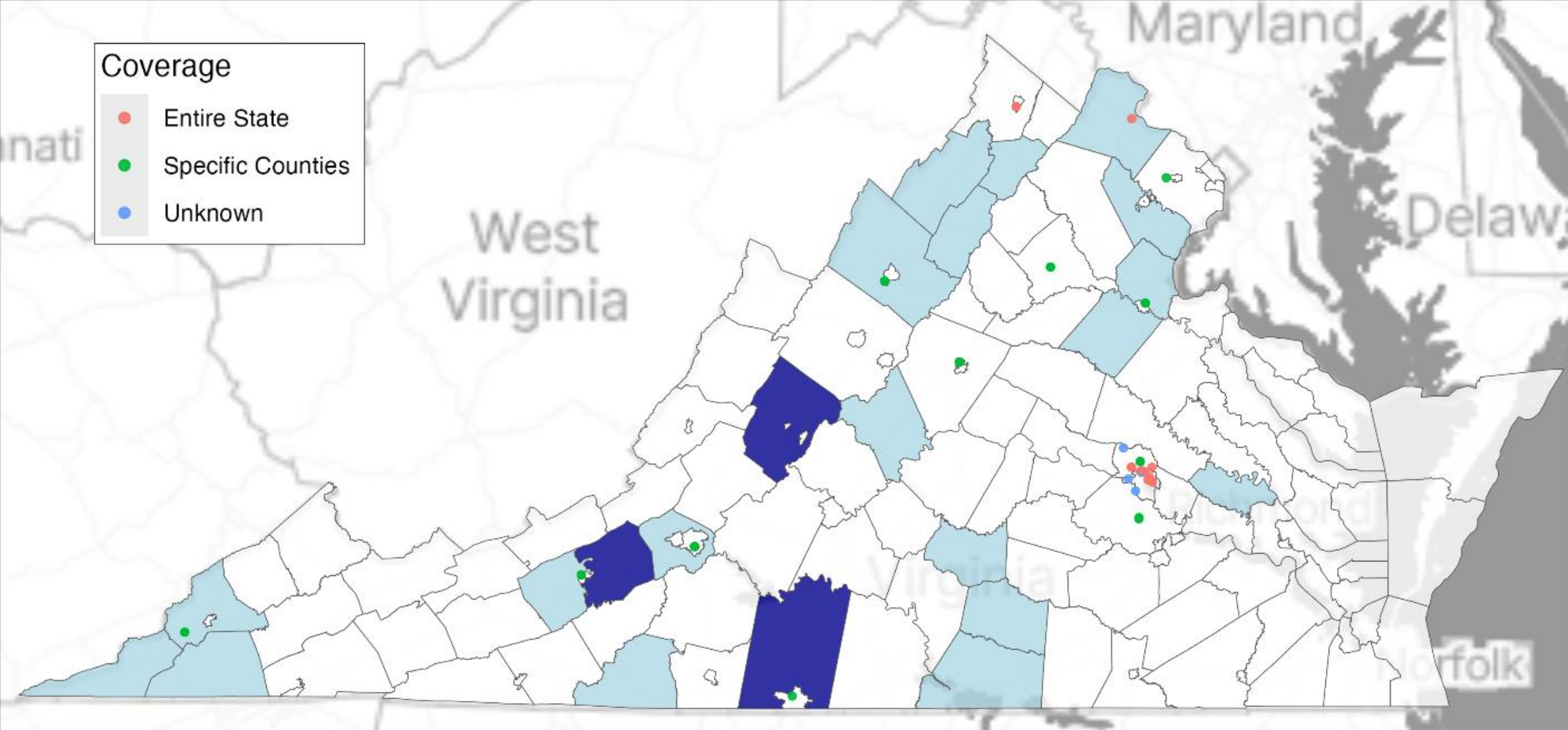To understand the ecological issues in the disability information

Interview Analysis

- 61 people from providers

- Each took 1 hour on average

- Answering: "What are challenges for providers"?

Locations of Interviewees' Agencies

Common Challenges by All Providers

Outreach and Advertisement

Information Customization: Language, Formats, and Jargons

Technology Management and Adoption Issues

Misinformation

State Agencies' Info Challenges

High **Staff Turnover**

Inconsistent Practices to Update Information

Decentralization in Policies

State Agencies' Info Challenges

High **Staff Turnover**

"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."

Recommendation 1: Enhance Staff Turnover Management

The **General Assembly** should endorse and fund the development of information systems or playbooks for HHRS.
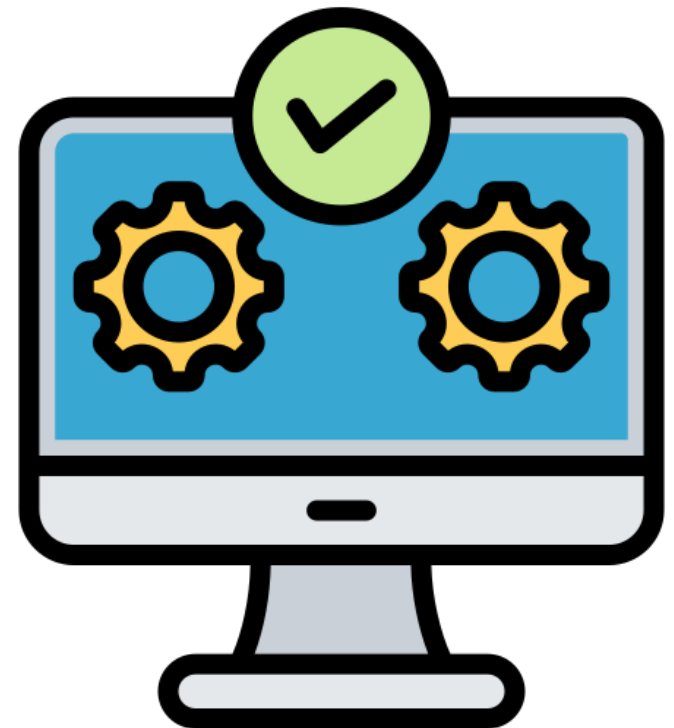
State Agencies' Info Challenges

Inconsistent Practices to Update Information

"We have reports that are due at various times. We've got weekly, we've got monthly, quarterly, those kinds of things, and then data can be pulled from that, but I wouldn't say that it's like everything has a set process at this time."

State Agencies' Info Challenges

Decentralization in Policies

"There's actually contracts with the MCOs to run regular Medicaid, so each of the MCOs does it differently. It's all the same information, but how one person may get it compared to a different person at a different MCO may get it could vary because there's different MCOs"

Recommendation 2: Automated Information Systems for Policy and Regulation Tracking

The **General Assembl**y should endorse and fund an automated information system to monitor and notify staff of policy or regulatory changes (e.g., dashboard, email alert system, or an alert module).

Recommendation 3: Information Quality Validation Training for State Employees

The **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 (Recommendations 1-2).

Local Agencies' (CSBs) Challenges

Emotional Work + **Crossing County/State Lines**

High Reliance on **Personal Networks**

Local Agencies' (CSBs) Challenges

Emotional Work + Crossing County/State Lines

"*We have the City of Danville and then Pittsylvania County that we provide services.* Sometimes we'll cross lines a little bit. We have these agreements with our neighboring CSBs. *[...] It might be somebody that lives just right across the Pennsylvania County line in another catchment area but they're closer to us than them, so they receive all their waiver services in Danville.*"

Recommendation 4: Enhance Visibility and Strategic Management of Work

The CSBs, DSS, VDH, and DBHDS should increase the visibility and strategic discussion about types of work conducted at local agencies (because many invisible work done across boundaries and emotionally).

Image from Financial Management
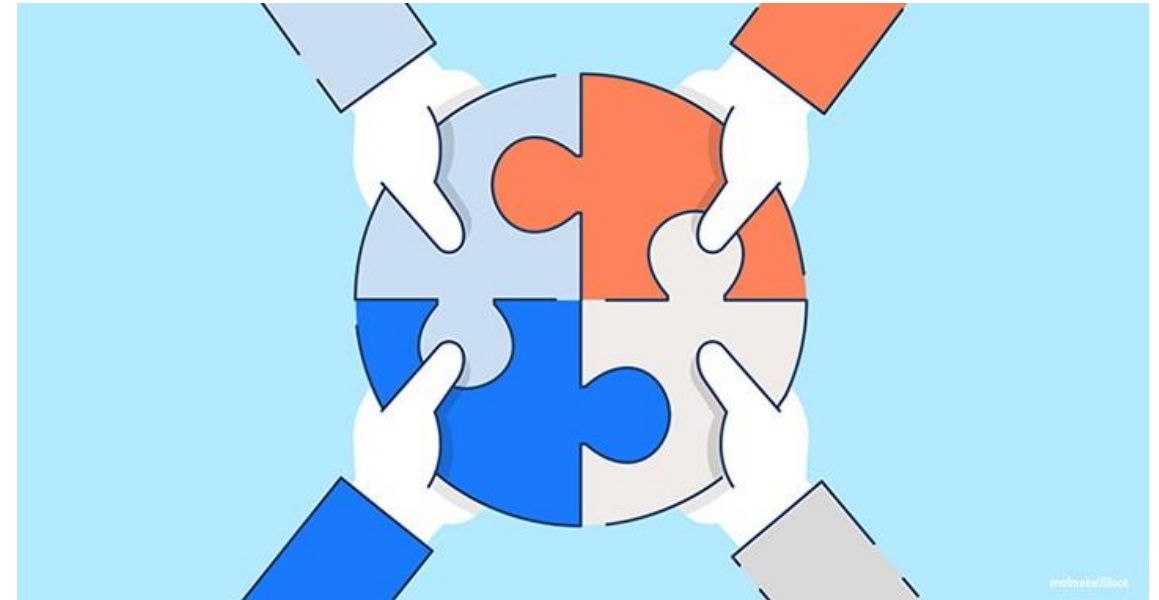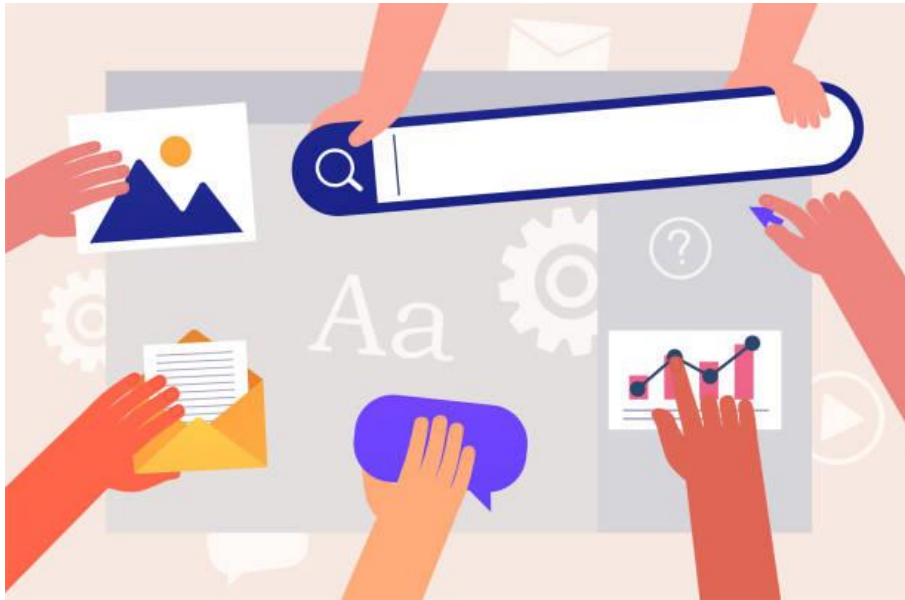
Local Agencies' (CSBs) Challenges

High Reliance on **Personal Networks**

"We don't have any formal connections in any way with people. We're not a partner of anybody specifically. We do interact with a lot of those folks."

Recommendation 5:
Dedicated information staff

The General Assembly should fund the establishment of **dedicated personnel at the DBHDS** and the **DMAS**, for providing standardized interpretation of Medicaid and other disability service-related policies.

Recommendation 6:
Leveraging Staff Knowledge and Networks

The **DBHDS** should support the establishment of a monthly forum or ongoing chat room, in which support coordinators can share best practices, raise concerns, and answer common questions.

Non-Gov Agencies' Info Challenges

Roles as **"Information Brokers"**

Trust Building to Reduce Stigma

Non-Gov Agencies' Info Challenges

Roles as "**Information Brokers**"

"*We also just get a lot of general phone calls because we're the partnership for people with disabilities, and people just call with random questions* about "How do I—I have a family member with a disability that's moving to Virginia, what do I do?" […] I mean, pretty much everything is about I need help in one way or another.

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

To better support providers and payers of disability-related information by implementing a single validation tool for advanced information systems.

Non-Gov Agencies' Info Challenges

Trust Building to Reduce Stigma

"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."

Recommendation 8:
Creation of stigma-free environment

The DMAS, DBHDS, DSS, and **VDH**, in coordination with the stakeholder community, should collaboratively develop and implement strategies for creating a stigma-free atmosphere to mitigate information access issues.

What We Did

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(State, Local, and Private)

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To understand the ecological issues in the disability information

Surveys

- **Provider survey** examines providers' sharing of information between agencies/websites in Virginia.

- **User survey** examines people's use of different kinds of information across diverse information sources

Survey Data

- Provider Survey
  - 95 complete responses (from State, CSBs, and Non-Profits)

- User Survey
  - 887 People with Disabilities or their Family Members
    - 68% White responders
    - 77% female
    - 57% from urban areas

Preferred Information Sources

Rank	Information Source	Classification	# of Respondents
1	Google (General Search)	Search Engine	182
2	Virginia 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
10	Facebook	Social Media	60

Preferred Info Sources: PPL w/ Disabilities

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

Preferred Info Sources: PPL w/ Medicaid

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

Preferred Info Sources: People of Color

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

Preferred Info Sources: PPL below Poverty Line

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
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

Recommendation 9:
Improve the capacity of popular government information sources

The DMAS, DBHDS, and 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.

INFORMATION

Recommendation 10:

Increased Monitoring of Quality Information

Because users acquire disability service information through Google searches and social media, **DBHDS** and **DMAS** should take proactive action and increase monitoring of information provided by these sources to mitigate misinformation or any conflicting information.

Image from WHO

What We Did

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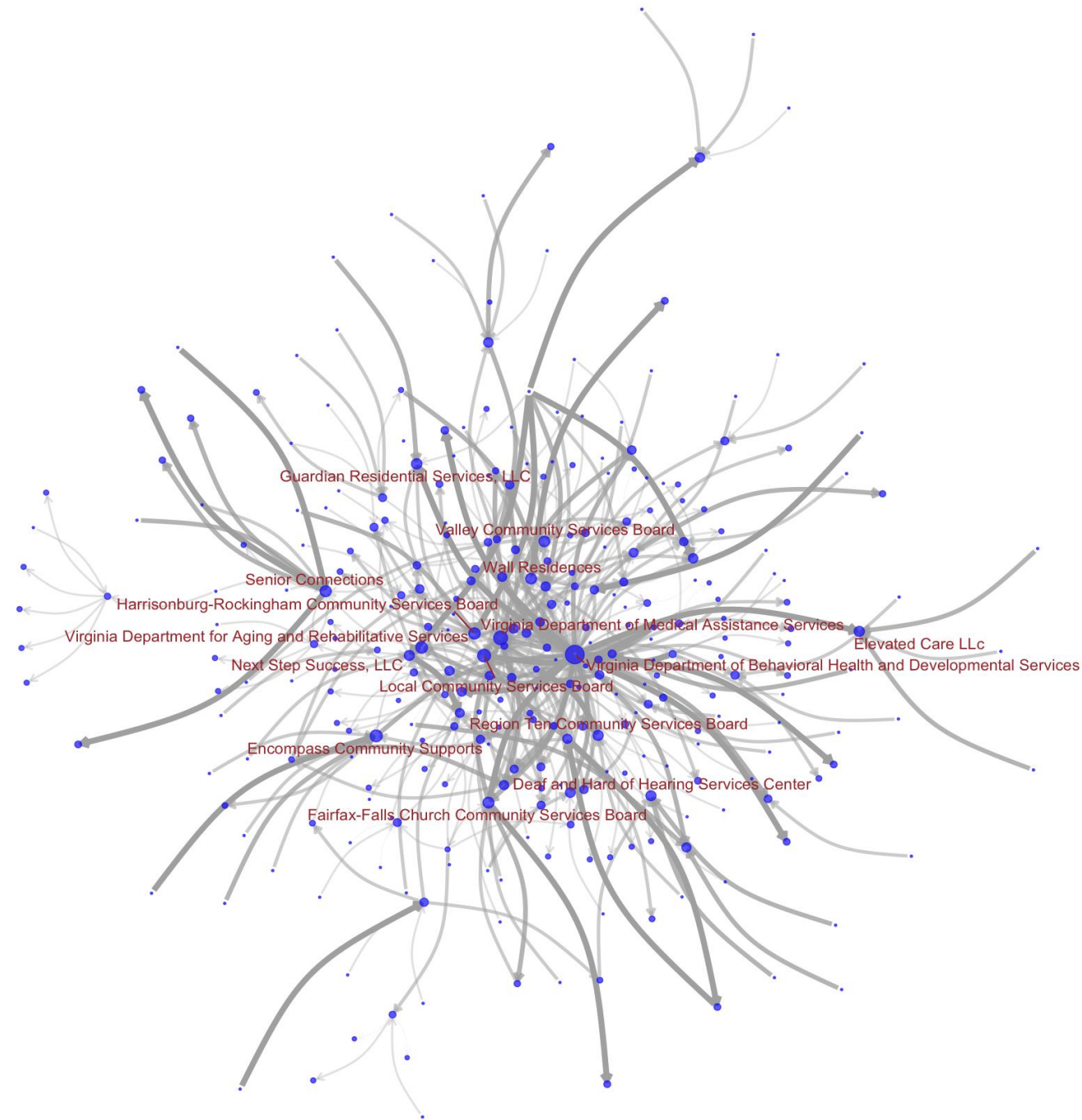To identify key information sources communicated

Network Analysis of Information Sources

To understand the ecological issues in the disability information

Providers' Information Networks

- **Dots**: info sources mentioned by respondents

- **Lines**: when responder says they use information from specific agencies

Overall Rankings based on Network Roles

Rank	Bridging Role	Using Other Sources	Used by Others
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

When it Comes to Medicaid Information Only

- More silos

- Reduced number of information sources
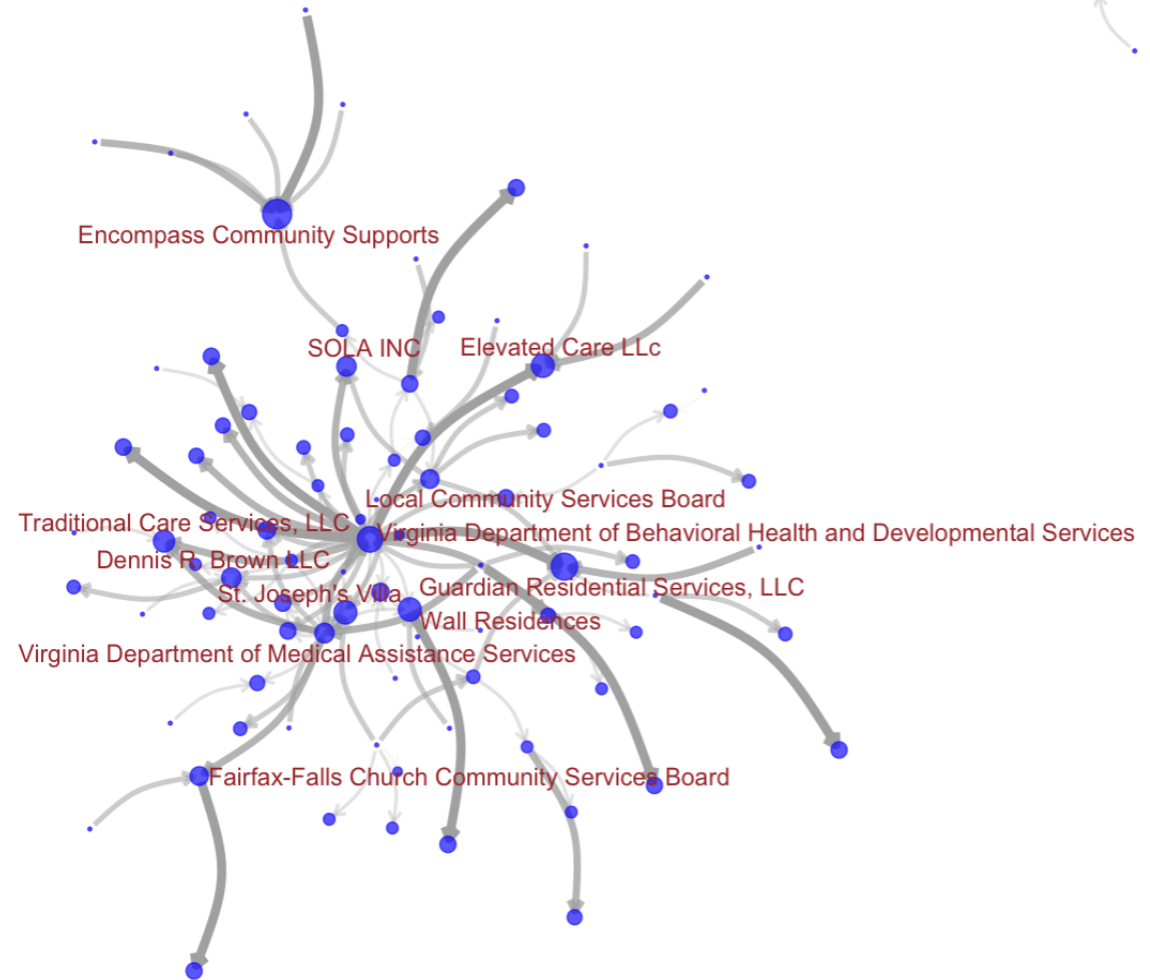
Roles of non-gov agencies increased in providing information to other agencies

| Rank	Bridging Role	Using Other Sources	Used by Others
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
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

Implications of Network Analysis

- Confirm Recommendation #3 that emphasizes the need for the increased networks between local agencies and non/for-profits
  - If state agencies' communications fall short, the rest of the agencies will face confusion and a loss of connections.

- When it comes to Medicaid information, state agencies need to put more resources into playing a leadership.
  - Confirm our Recommendations #4 and #5 focused on outreach and campaign.
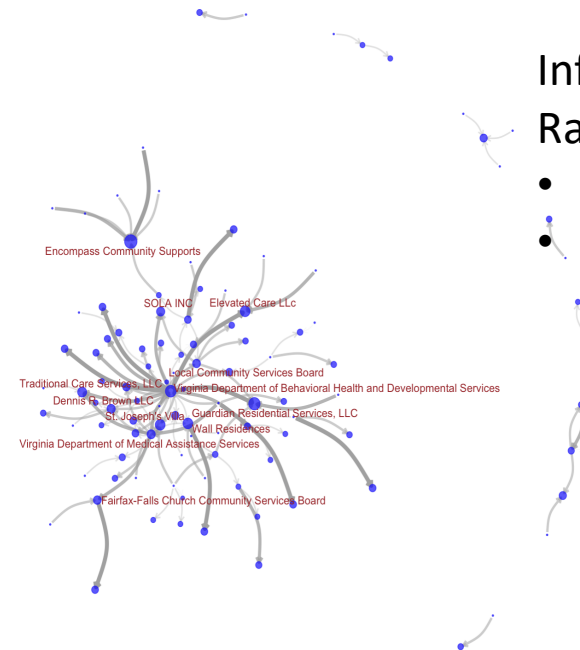
It's Also Possible to Measure "Info Fragmentation"

For each information network, it is possible to measure how much the network is centralized.
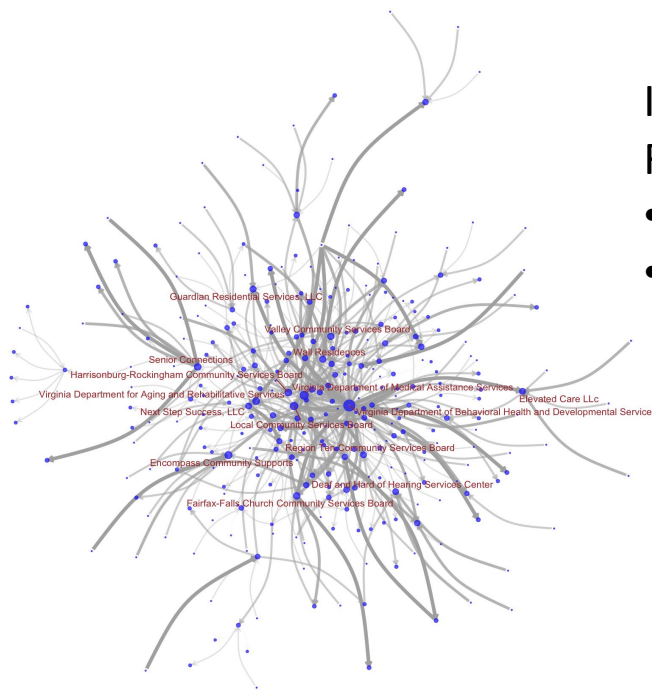
Information Fragmentation Rates (Overall kinds)
- As info sources: **6.25**
- As bridges: **7.14**

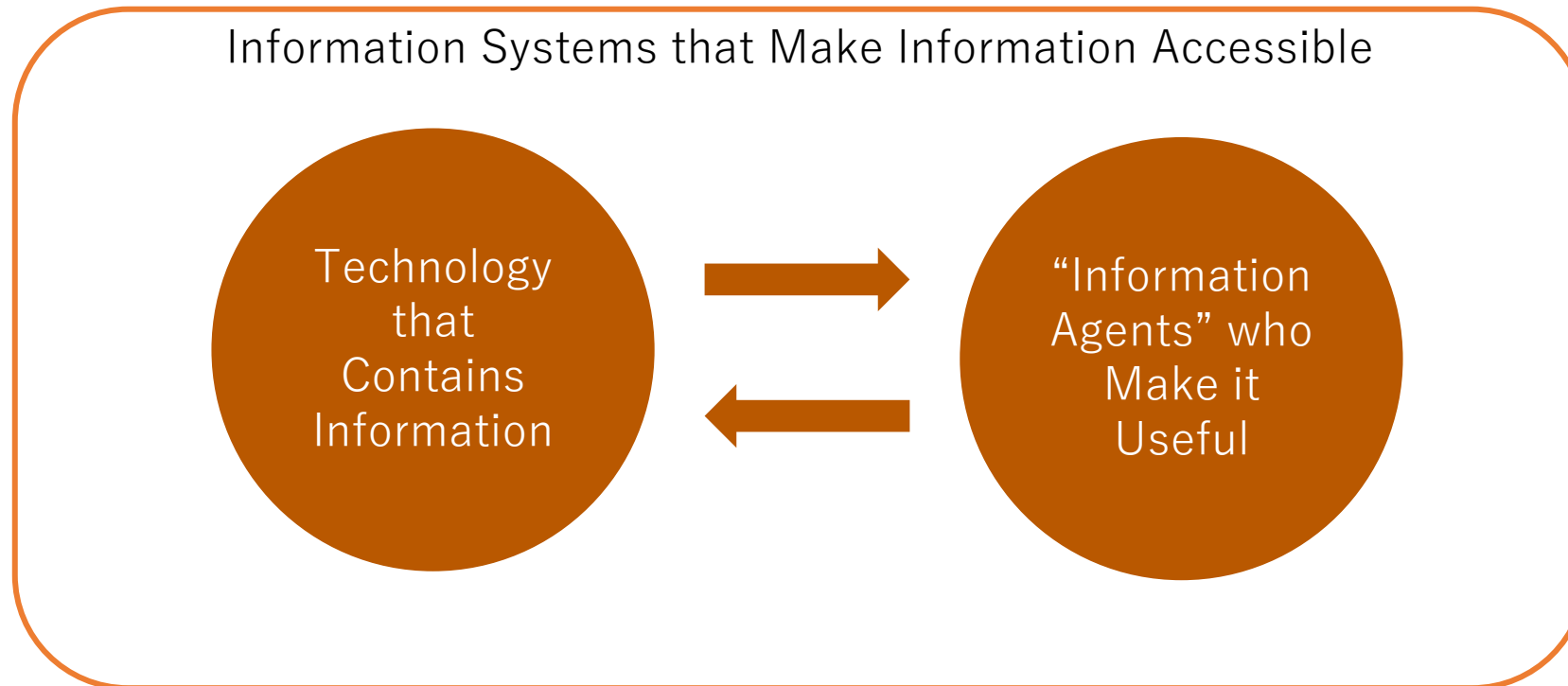Information Fragmentation Rates (Medicaid Only)
- As info sources: **7.14**
- As bridges: **100**

Implications (Cont'd)

- By making use of the "Information Fragmentation Rates":

  - It becomes possible to **monitor** the information ecological health over time
    → directly affecting people's info access

  - It becomes possible to **compare** the ecological status between different kinds of information (e.g., Medicaid-related info vs. policy info).

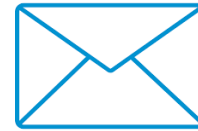# Our Findings and Recommendations focus on Improving a Broader Information Ecosystem

Information Systems that Make Information Accessible

Technology that Contains Information → "Information Agents" who Make it Useful

Thank You
Q & A

cil. Community Informatics Lab

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Virginia Board for People with Disabilities

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