Council Meeting Minutes

February 25, 2022

**Council Members Present:**
- Shontie Brown*
- Allison Bynum*
- Jody Cheek*
- Roddey Coe*
- Jennifer Coleman*
- Kezia Cox*
- Sarah Cripps*
- Ryan Durham*
- Will Edwards*
- Diamond Grigsby*
- Lesley Guillaran*
- Alicia Hall*
- Chrissy Hood*
- Clancey Hopper*
- Lisa Johnson*
- Edward Mitchell*
- Tecia Puckett Pryor*
- Brigham Scallion*
- Brent Wiles*
- Martez Williams*
- Alison Gauld, Dept. Special Education
- Jacqueline Johnson, Dept. of Health
- Julie Johnson, Voc. Rehab. Services
- Lisa Primm, Disability Rights TN
- Mark Liverman, Dept. Mental Health & Substance Abuse
- Carrie Brna, Dept. of Intellectual and Developmental Disabilities
- Bruce Keisling, UT Center for Developmental Disabilities (UTCDD)
- Elise McMillan, Vanderbilt Kennedy Center
- Don Watt, THDA

**Visitors Present:**
- Elliott Pinsky, Behavioral Health Foundation

**Council Members Absent:**
- None

**Staff Present:**
- Lauren Pearcy
- Lynette Porter
- Alicia Cone
- Cathlyn Smith
- Brian Keller
- Jolene Sharp
- Emma Shouse Garton
- JoEllen Fowler
- Mildred Sparkman

**Staff Absent:**
- Ashley Edwards

**Guests Present:**
- Stephanie Cooper (MHSAS) Asst. Director
- Bonnie McBride (UT CDD) Grad Student
- Taylor Napier (UT CDD) Grad Student
- Emily Lanchack (VKC) Presenter for Pathfinder
- Sheena Adams-Avery (VKC) Presenter for Pathfinder
- Megan Hart (VKC) Presenter for Pathfinder

*denotes Governor appointed citizen*
9:00 a.m. Opening, Introductions & Agenda Review

The Council is conducting this meeting by electronic means of communication (Zoom for Government) in order for the Council to safely conduct its statutory duties. A quorum of the Council members cannot safely meet physically because of the coronavirus/COVID-19 pandemic. The council will reassess the need to meet by electronic means for future meetings.

Council Chair, Tecia Puckett Pryor, called the meeting to order after ascertaining there was a quorum at 9:01 a.m. Tecia welcomed everyone and facilitated introductions of newly appointed members and staff:

- Kezia Cox*, East Tennessee Development District
- Will Edwards*, East Tennessee Development District
- Diamond Grigsby*, Member At-Large
- James Dunn, TN Commission on Aging and Disability
- Julie Johnson, Vocational Rehabilitation
- Brian Keller, General Counsel and Public Policy Director
- Ben Mangrum, Intern from Vanderbilt Next Steps

Tecia then reviewed the agenda.

9:20 a.m. Business Items

Approval of September 2021 Minutes and February Meeting Agenda

The September 2021 Council meeting minutes were emailed to all the Council members prior to the February 25, 2022 Council meeting to give members an opportunity to review before the meeting. Tecia asked if there were any amendments to the agenda or September 2021 minutes. Lauren noted the addition of the statement above about meeting electronically to the beginning of the September minutes. Tecia called for a motion to accept the agenda and the minutes, as edited, from the members present at the September meeting. **Sarah Cripps moved to accept the February 25, 2022 agenda and amended September 2021 minutes and Clancey Hopper seconded the motion. There was no further discussion and the motion carried.** Members voted via a Zoom poll: 92% voted yes, 8% abstained.

Executive Director Report

Lauren Pearcy, Executive Director, highlighted some of the outstanding things that have happened since the Council met in September.

First, a recognition of Council members: Lauren gave a few examples not only to celebrate our members, but in hopes it will give everyone, especially new members, a sense of the RANGE of ways members can engage:

- Thanks to Brigham Scallion's work in his community, Dyersburg State Community college has the first inclusive higher education program on a community college campus in Tennessee. This happened thanks to the work of Brigham, funding from the Dept. of Intellectual and
Developmental Disabilities (DIDD) new program “Tennessee Believes,” and many, many years of groundwork laid by the Inclusive Higher Education Alliance. Elise McMillan, co-director of the Vanderbilt Kennedy Center and our Council member, and Wanda Willis, our former leader, worked behind the scenes to lay that groundwork.

- The Dept. of Environment and Conservation has launched an initiative called “Access 2030” to make all state parks accessible within the next decade. They have included the Council and DIDD on their steering committee, and most impressively, have asked people with disabilities to tour the parks with them to get a true sense of what is needed – beyond an ADA checklist. Alison Bynum attended one of these tours with her daughter who uses a wheelchair and has other accessibility needs that the parks would not have thought of, like an adult-size changing table. Alison is now quoted regularly by their leadership team because of the meaningful feedback she gave. This is exactly the role we hope Council members will play, informing the system with your lived experience.

- There will be more about changing tables in the public policy report, but Lauren wanted to recognize a role one member played that would go unrecognized otherwise. Brent Wiles has helped staff strategize and build relationships that we could not have done without him. If you don't know him yet, Brent has long experience in legislative policy work and it has been so valuable to be able to call on his expertise when we hit roadblocks.

- Finally, Lauren thanked all members for their input as staff have worked with the Dept. of Education on funding reform. Under Deputy Director Lynette Porter's leadership, the Council was part of a stakeholder group about students with disabilities. We leaned heavily on members' input. From a personal perspective, it was powerful to see members' responses build on each other via email. That's what the Council is all about. The most common way a lot of members engage is through your input. Every story you tell us, article you send, and question you ask helps us.

Lauren then recognized several staff contributions since the last meeting.

- The communications work staff has done was chosen as the national spotlight by our national association, National Association for Councils on Developmental Disabilities (NACDD). Staff also launched the Council's first ever billboard campaign, which entailed a lot of work and creative problem solving by JoEllen, Mildred, Lynette, and Jolene. Look for one on I-65 South, right before 100 Oaks mall, when in Nashville!

- Staff also recently submitted our federal reports, which is a painstaking process complicated this time around by a new vendor and reporting system. Thank you to Alicia for being so organized that we had to wait for our federal partners to be ready to accept.

- Staff also ZEROED OUT our budget allocation last year, to the penny, which is a feat any year but especially after several years of COVID throwing wrenches in our spending patterns. We are so grateful to Lynette's leadership in this area.

Lauren highlighted two projects that Council members voted to fund before the pandemic began. The Council had an allotment to spend within 2 years instead of 3 because of a federal policy change, so these were bigger investments than normal, and they are paying off:
• TN Center for Decision-Making Support has not only launched and started fielding hundreds of inquiries, they have reversed 4 conservatorships that were no longer needed. This sounds simple but takes a whole lot of legal and advocacy expertise. It really comes down to mediation a lot of the time – and without a team dedicated to this, thanks to the Council's grant, it would not have happened. Thank you to Tecia and Lesley for being part of this project's advisory committee.

• TN Disability Pathfinder will present later today, when members will see how much our investment has paid off.

Here are a few things on the horizon:

• Committee meetings will focus on new ways to engage members of the committees. There is also a new question about this on the evaluation. Think about how staff can hit the right balance of engaging members enough to help them feel familiar with the work (not coming to it cold each meeting) and not overburdening them between meetings.

• The State Plan Progress review will be postponed until the next meeting in April.

• Also in April, staff will ask members all to fill out a “committee interest survey” so that we have data about your interest in each of our goal areas. Staff may not be able to align members’ interests perfectly, but they want to have that data on hand and work from it.

• Finally, members may have noticed this already: on the last Friday of every month, Lauren will send an email update. The goal is not to duplicate Council newsletters, but to keep everyone updated between meetings. So much happens, and it's hard to pack it all into the meeting reports. Council member feedback on this is important.

Executive Committee Report

Tecia noted for new members that the executive committee has 5 members, the chair, vice-chair and the chairs of the three committees. There was a recent change in committee leadership. Tatum Fowler's term came to an end this summer, and he has been replaced by Edward Mitchell as chair of the communications committee.

The executive committee is getting into a groove with Lauren as the new Executive Director and enjoying working with her.

The committee is working with staff on a document about members’ role with the Council and a road map to how the Council is set up, as well as different paths to leadership. The hope to share it by the meeting in April.

Budget/Operations Report

Deputy Director Lynette Porter reported that the Governor presented the Council's FY23 budget to the legislature on January 31st as a part of his budget packet. The state budget is the approved operational plan for how we spend our federal dollars. It will be finalized when the Legislature passes the state budget. We do not expect any issues. Federally, our two full awards are fully obligated and our FY22 award is not yet passed in Congress. We are under a continuing resolution, which means we are given a partial award until the budget passes.
We have received notice from the Secretary of State of an upcoming audit of our records and records-management process. This is the first audit of this nature since becoming an agency in 2016. All staff will be involved in preparing for the audit.

Clancey Hopper asked if the Council is working on any new grants. Lynette replied, not to her knowledge. Currently staff are focused on the grant continuation cycle for next year. For new members, Lynette explained how the Council operated before becoming a state agency and what has changed since becoming a free-standing state agency. Our agency of 10 staff is now responsible for all of the same agency level reporting, audits, and contract monitoring as much larger agencies (example: an agency of 3,000 staff).

Audit Committee Report
Audit committee chair, Alicia Hall, reported that in December, the committee reviewed the documentation of the agency’s annual risk assessment and found agency controls to be adequate. She reminded the Council and staff of the responsibility to report concerns of fraud, waste, and abuse and that a notice of the process of reporting concerns was sent to members and staff earlier in January. The notice will also be distributed with the minutes of the meeting. For the April meeting, the committee will be reviewing the agency process for staff acknowledgement of the code of conduct required for all state employees.

9:40 a.m. Adjournment to Committee Meetings & Break

10:50 a.m. Committee Report Outs

Minutes from committees are attached to these minutes.

- Leadership Development Committee (Lisa Johnson, Chair)
- Public Policy Committee (Lesley Guilaran, Chair)
- Communications Committee (Edward Mitchell, Chair)

11:06 a.m. Pathfinder Update

Elise McMillan, Vanderbilt Kennedy Center, introduced Pathfinder staff and the information they will share in their presentation. The update will share key outcomes from the TN Disability Services Study funded by the Council. Emily Lanchack will share highlights from the survey, then Megan Hart and Sheena Adams-Avery will demonstrate the new Pathfinder website.

Emily Lanchack gave an overview of the TN Disability Services Study and shared key outcomes. She went over the 5 research areas they chose, which involved learning what experiences are most important to people with disabilities and their families, taking those experiences and learning how familiar they are with programs and services, and then generally, what are their experiences finding those services, what primary sources they use, and finally, what are their recommendations for new resources. They then reviewed how those answers vary based on different characteristics or roles.

They aligned surveys for 8 stakeholder groups and followed up with 26 focus group interviews. Over 3,000 people responded to survey, with almost all counties represented.
Emily shared the results, which indicated people with disabilities and family members still have a hard time finding the information and help they need. Professionals and healthcare providers also find it difficult to find the information they need, highlighting the need to partner with these groups.

The sources that are most helpful for individuals or families were internet searches, social media, doctors, and therapists. For professionals, internet searches, other professionals, conferences, and workshops were the most used resources.

Overall, people are most likely to use websites where they can search for resources, like Pathfinder, or a smartphone app, which is now available on MyTN and is integrated with voiceover. The good news is we already have a wonderful foundation. We can build on this foundation by optimizing websites, educating people on the best ways to search for information, and looking for ways to interact with professionals at conferences and workshops, increasing our presence at these events.

Members discussed making sure parents are informed about Pathfinder & MyTN app by sharing with special education teachers. They were struck by professionals having difficulty finding information. They may not look for resources beyond what they already know about, so training staff is important. Pathfinder is already working with departments on this.

Megan Hart demonstrated the new Pathfinder website. The home page is more user-friendly, features accessibility tools, and translations into several languages. Camino Seguro has been incorporated since Spanish translation is an option.

Visitors can create a profile, anyone can use it without creating a profile, but there are additional features if they do. There are five filters to guide visitors through the website: age/life stage, topics of interest, diagnosis, payment options, location.

Organizations can claim their listing and provide changes as well as list upcoming events. They can also submit information about an agency not already on website. Pathfinder welcomes suggestions, as they are always improving.

Sheena Adams-Avery discussed ways to engage with Pathfinder and share information about Pathfinder through media and communications. Whatever platform you use, the media pages tell you a lot about the agency and allows all to engage with the agency. She then reviewed their media page. They have new print resources and Pathfinder swag that can be ordered. They are also on Facebook, Twitter, and Instagram. Each platform caters to specific demographic, so they try to gear their information to the demographic of each platform.

12:09 p.m. Legislative Report

Brian Keller, General Counsel and Policy Director, gave a brief presentation on important policy issues. He covered the Council’s role in public policy as dictated by the Developmental Disabilities Act (DD Act). Brian discussed the difference between educating policy makers, as mandated by the DD Act, and lobbying, which is prohibited by other federal law. He then described a bill in the legislature right now that is being led by Council members and invited Council members to discuss their experiences educating lawmakers.
Members talked about the next steps for the changing tables bill and encouraged everyone to reach out to their legislators. They suggested letting organizations in your area know it’s important to you also, and gain local momentum. It can help with legislation and also help avoid the need for legislation. For example, some local government/agencies respond well and just do the instillation. When in doubt, ask the Council. If members decide to ask for support rather than educating, do it as a citizen, not a Council member.

12:40 p.m.  Wrap Up

Tecia reminded members to complete the evaluation form this week, which will be e-mailed immediately following the meeting. The next Council meeting will take place on Friday, April 22, 2022, hopefully at the Embassy Suites Nashville Airport. For new members, the Council provides a hotel room and reimburses for mileage and meals. There will be more information about travel in the coming weeks.

12:43 p.m.  Public Comment

Visitors to the Council meeting were invited to make public comment.

12:55 p.m.  Adjournment

A motion for adjournment was made by Sarah Cripps and seconded by Edward Mitchell. The motion carried and the Council meeting was adjourned at 1 p.m. Members voted via a Zoom poll: 95% voted yes, 5% abstained.

Upcoming Meeting Dates

2021 Council Meeting Dates
- Council Meeting: Friday, April 22, 2022
- Council Meeting: Friday, September 16, 2022
- Council Retreat: Thursday & Friday, November 3-4, 2022

Respectfully submitted by: JoEllen Fowler, Office Resources Manager

Approved by: Lauren Pearcy, Executive Director
To: Members and staff of the Council on Developmental Disabilities
From: Alicia Hall, Audit Committee Chair
Date: February 15, 2022
Subject: Responsibilities related to preventing, detecting, and reporting fraud, waste, and abuse

Under its charter, the Audit Committee is responsible for formally reiterating, on a regular basis, to the Council members and staff, their responsibilities for preventing, detecting, and reporting fraud, waste, and abuse.

The TN Comptroller of the Treasury defines fraud, waste and abuse in the following ways:

- **Fraud** – An intentional deception that violates a law or the public trust for personal benefit or the benefit of others.
- **Waste** – Behavior involving the extravagant, careless, or needless use of government funds, property, and/or personnel.
- **Abuse** – Behavior involving the use of government funds or property that a prudent person would not consider reasonable and necessary business practice given the facts and circumstances.

Duty to inform the public:

All state agencies, as well as those agencies receiving community grant funds, are required to call attention to the State Comptroller's Toll-Free Hotline by displaying in a prominent place signs with the following language:

*If you observe an agency director or employee engaging in any activity which you consider to be illegal, improper or wasteful, please call the State Comptroller's Toll-Free Hotline: 1-800-232-5454.*

There is also a mechanism for citizens and public officials to report observations electronically on the State Comptroller’s website: [www.comptroller.tn.gov](http://www.comptroller.tn.gov)

**Duties as Council members and staff:**

Annually, the Audit Committee assesses the risk of fraud at the agency, including documentation of the results of management risk assessments and internal control structure.

Additionally, Council members and staff have a duty to immediately report allegations of fraud, waste or abuse at the agency. Reporting can be done through any of the following confidential routes:

| Contact the Chair of the Audit Committee | Current contact information can be found in every Council member meeting packet |
| Contact the Executive Director of the agency | Lauren Pearcy: 615-532-6550, lauren.j.pearcy@tn.gov |
| Contact the State Comptroller's office | State Comptroller’s Toll-Free Hotline: 1-800-232-5454 |
|  | Online reporting forms can be found at [www.comptroller.tn.gov](http://www.comptroller.tn.gov) |
Council Leadership Development Committee

Location: Zoom Meeting
Date: Friday, February 25, 2022
Time: 9:40 A.M. CDT

Present: Lisa Johnson, Alison Bynum, Ryan Durham, Alicia Hall, Carrie Brna, Alison Gauld, Julie Johnson, Jody Cheek, Kezia Cox, Mark Liverman, Brigham Scallion and Bruce Keisling
Absent:

Staff: Cathlyn Smith, Alicia Cone
Guests: Bonnie McBride from UT LEND, and Taylor Napier from UT LEND

1) Call to Order/Introductions/Agenda
   • After ascertaining there was a quorum (50% of Committee members), the committee meeting was called to order. Consent agenda – The agenda for the meeting was shared. Alicia H. moved to approve the agenda. Brigham S. seconded. Approved. Yes, votes were Bruce K, Alicia H., Alison B. Brigham S., Jody C., Kezia C., Ryan D., Julie J. and Carrie B., No one voted “no”.

2) Partners in Policymaking:
   o Current class has three sessions remaining with graduation scheduled for April 7, 2022
   o Our next cohort application portal on our website will launch and intake of applications will begin and run March 1-31, 2022. Our goal is to fill 30 slots for the next cohort which will begin in Sept. 2022.
   o Once the application intake ends applications will be organized on a spreadsheet for review and elimination based on eligibility. Please note:
     - Eligibility criteria requires that the participant must be an adult with a disability or a family member (primary caregiver) of a person with a disability.
     - Participant must commit to attend all sessions and complete necessary homework and other documentation for participation.
     - Please share information about Partners within your networks and communities. We will be sending out information via our various newsletters announcing the application period. We are working to recruit participants from populations that we haven't had in the past. Those populations include persons of color, male participants, and people from outside of the Middle TN area.
   o Please volunteer to serve as application reviewers for the cohort selection. Volunteers are Alicia H., Julie J., Lisa J., Ryan D, and Jody C.
     - Timeline:
March 1-31, 2022, applications received (may extend time based on number of applications we get in)
First part of April spreadsheet will be compiled for anonymous review of applications.
Mid-April – Spreadsheet will be shared with reviewers for review and selection of their top 30 applicants.
End of April – Final class selection; selected applicants notified along with those we did not select this round.
May – New cohort announced
  - Partners Summit – working and planning this event based on information and input from Partners Graduates from an online survey

Leadership Academy for Excellence in Disability Services
  - Currently planning for May/June cohort start for the next class. This will be a hybrid format this year with some in-person and virtual classes.
  - Next steps will include getting the MOU from DOHR and contacting agencies to recommend personnel for the class.
  - LAEDS Longitudinal Survey to be completed by Dr. Keisling and staff at UT-CDD. We hope to have this completed by 6.30.2022

Scholarship Fund
  - We have continued to get applications for individual and organizational assistance for conferences and meetings. Individuals have stated that without this fund they would not have been able to network and learn about the disabilities that affect them and the conference sessions and experts that they get to hear from. As of this week we have a little over $642 remaining in unallocated funds.

3) Motion to Adjourn

At 10:30 a.m. Brigham S. moved for adjournment. Julie J. seconded. Approved. Bruce K., Alicia H., Carrie B., Jody C., Alison B., Ryan D, Kezia C., Julie J., and Brigham S. voted yes, there weren't any “no” votes.

Prepared by: Cathlyn Smith
Council Public Policy Committee

Location: Virtual (Zoom)  
Date: Friday, February 25, 2022  
Time: 9:40 A.M. CDT

Present: Lesley Guilaran (Chair), Jennifer Coleman (member), Shontie Brown (member), Roddey Coe (member), Sarah Cripps (member), Clancey Hopper (member), Martez Williams (member), Russette Marcum-Embry (TCCY), Jacqueline Johnson (DOH)

Absent: Brent Wiles (member), Lisa Primm (DRT)

Staff: Lauren Pearcy, Brian Keller, Mildred Sparkman

Visitor: Elliott Pinsley, Behavioral Health Association TN

1) Call to Order  
After ascertaining there was a quorum, Lesley Guilaran, Chair, called the meeting to order at 9:45 a.m. CDT

2) Consent Agenda  
Lesley Guilaran shared the agenda for the meeting and asked for a motion to approve. Clancey motioned and Roddey seconded. Lesley led a roll call vote:

1. Lesley Guilaran – yes  
2. Russette Marcum-Embry – yes  
3. Jennifer Coleman – yes  
4. Clancey Hopper – yes  
5. Roddey Coe – yes  
6. Martez Williams – yes  
7. Sarah Cripps – yes

3) Introductions  
Lesley Guilaran facilitated introductions.

4) Bill Tracking and Priority Bills  
Brian Keller led a discussion about bill tracking using software and announcing automated bill reports to committee members and other members who opt in. Then, Brian highlighted the Council’s priority bills:

- Changing Tables Bill amended to put tables in 35 rest areas across the state and grant program administered by DIDD for private businesses. Goes to committee at 1pm on 3/1.
- Respite pilot bill  
- Remove offensive language “deaf and dumb” from state code  
- Requirement for ACT scores for 4 year university programs may impact inclusive higher education programs
- Rx label act: must be accessible to the patient
- Bill to end subminimum wage for people with disabilities in TN
- Bill that would criminalize student assault on teachers, including spitting
- VR bill codifying changes to TN Rehabilitation Centers. **We will ask VR to present at the April meeting.**

5) **Committee Input for Future Work**
   Not discussed

6) **Adjournment**
   Lesley Guilaran, Chair, called for a motion to adjourn at 10:40 a.m. CDT

Prepared by: Lauren Pearcy and Mildred Sparkman
1) **Call to Order – Approve Agenda**

After ascertaining there was a quorum, Edward Mitchell, Chair, called the meeting to order at 9:40 a.m.

The committee reviewed the meeting agenda. Tecia Puckett Pryor moved to approve the agenda. The motion was seconded by Chrissy Hood. A roll call vote was held:

- Tecia Puckett Pryor – Yes
- Shannon Nehus – Yes
- Diamond Grigsby – Yes
- Don Watt – Yes
- Chrissy Hood – Yes
- Shontie Brown – Yes
- Will Edwards – Yes

2) **FY22 Outcomes Review**

Jolene Sharp, Chief Public Information Officer, led the committee through an overview of communications outcomes through Feb. 1, 2022, including reviewing the pace of growth of all major communications platforms (social media, email newsletters, *Breaking Ground* magazine subscriptions). The committee discussed the need for every Council member to be an ambassador in their communities to share our publications and encourage people in the disability community to subscribe. Council members shared several ideas, including:

- Asking local libraries to offer copies of *Breaking Ground* magazine
- Sharing online link to subscribe to email newsletters
- Sharing social media content to personal or local disability pages

The committee discussed the importance of short, storytelling videos as a key factor in growing social media reach and engagement and helping to reshape expectations for what's possible.
3) **Website Reorganization Overview**
Emma Shouse Garton, Public Information Specialist, reviewed with the committee changes still underway for the Council's website. These changes are being made in response to previous communications committee input that the website should be the top priority for updates. Among the changes highlighted:
- Simpler navigation
- More visuals (like pictures of staff, a Council member map)
- Removal of outdated content (keeping top highlights of past work on an “impact timeline”)
- Removal of information available elsewhere or references to specific services – focusing instead on linking to Pathfinder
- Adding content about the Council's unique role and current work

The committee was encouraged to review ongoing updates before next meeting and provide any feedback on what's working well and what's not.

4) **Committee Input for Future Work**
Jolene Sharp reviewed plans for future storytelling videos with new accessibility features. Council members suggested ideas for these videos, including:
- Very short format videos that can be shared on other platforms like TikTok or LinkedIn
- Addressing the stigma of job loss – telling the story of someone who lost a job and was able to start again
- Enabling tech – ways people with disabilities and families can use technology to support independence, including augmentative and alternative communication (AAC) devices – show both within services and off-the-shelf options

5) **Adjournment**
At 10:40 a.m., Edward Mitchell, Chair, held a vote to adjourn. Tecia Puckett Pryor made a motion to adjourn. Diamond Grigsby seconded. A roll call vote was held:
Tecia Puckett Pryor – Yes
Shannon Nehus – Yes
Diamond Grigsby – Yes
Don Watt – Yes
Chrissy Hood – Yes
Shontie Brown – Yes
Will Edwards – Yes

Prepared by: Jolene Sharp
OUR QUESTIONS

1. What experiences are most important to individuals with disabilities and their families?

2. How familiar are individuals, families, and professionals with disability-related programs and services in their community?

3. How do they characterize their experiences trying to locate needed information and services?

4. What are their primary sources for disability-related information?

5. What are their recommendations for new resources to address these concerns?

6. How do the responses to Q1-Q5 vary based on disability type, participant demographics, geographic locale, and stakeholder role?
OUR APPROACH

Aligned Surveys of 8 Stakeholder Groups

December 2020 - April 2021

Follow-up with 26 Focus Group Interviews

March 2021 - July 2021

COMPLETED SURVEYS STATEWIDE

Total = 3,088+

INDIVIDUALS WITH DISABILITIES: 726
Parents: 1081
Siblings: 73
Loved Ones: 63

FAMILIES: 1,217
Parents: 1081
Siblings: 73
Loved Ones: 63

PROFESSIONALS: 1,099
Educators: 504
Providers: 294
Agencies: 212
Healthcare: 89
OUR QUESTIONS

1. What experiences are most important to individuals with disabilities and their families?

2. How familiar are individuals, families, and professionals with disability-related programs and services in their community?

3. How do they characterize their experiences trying to locate needed information and services?

4. What are their primary sources for disability-related information?

5. What are their recommendations for new resources to address these concerns?

6. How do the responses to Q1-Q5 vary based on disability type, participant demographics, geographic locale, and stakeholder role?
Overall, how easy is it for you to find the information you need?

- **Individuals w/ Disabilities**
  - Very hard: 14%
  - Somewhat hard: 39%
  - Somewhat easy: 34%
  - Very easy: 13%

- **Parents**
  - Very hard: 24%
  - Somewhat hard: 51%
  - Somewhat easy: 22%
  - Very easy: 4%

Overall, how easy is it for you to find the help you need?

- **Individuals w/ Disabilities**
  - Very hard: 34%
  - Somewhat hard: 44%
  - Somewhat easy: 18%
  - Very easy: 3%

- **Parents**
  - Very hard: 26%
  - Somewhat hard: 48%
  - Somewhat easy: 15%
  - Very easy: 11%

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In the past year, how often did you need information or help related to serving individuals with disabilities, but did not know where to get it?

- **Educators**
  - Often: 9%
  - Sometimes: 45%
  - Rarely: 27%
  - Never: 19%

- **Providers**
  - Often: 11%
  - Sometimes: 46%
  - Rarely: 27%
  - Never: 16%

- **State Agencies**
  - Often: 11%
  - Sometimes: 43%
  - Rarely: 27%
  - Never: 19%

- **Healthcare Providers**
  - Often: 17%
  - Sometimes: 62%
  - Rarely: 16%
  - Never: 6%
OUR QUESTIONS

1. What *experiences* are most important to individuals with disabilities and their families?

2. How *familiar* are individuals, families, and professionals with disability-related programs and services in their community?

3. How do they characterize their *experiences* trying to locate needed information and services?

4. What are their *primary sources* for disability-related information?

5. What are their *recommendations* for new resources to address these concerns?

6. How do the responses to Q1-Q5 vary based on disability type, participant demographics, geographic locale, and stakeholder role?

WHAT SOURCES OF INFORMATION OR RESOURCES ABOUT DISABILITY DO YOU FIND MORE HELPFUL?

INDIVIDUALS AND FAMILIES

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<thead>
<tr>
<th></th>
<th>Individuals</th>
<th>Parents</th>
<th>Siblings</th>
<th>Loved Ones</th>
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<tbody>
<tr>
<td><strong>First Choice</strong></td>
<td>Internet searches</td>
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<td><strong>Second Choice</strong></td>
<td>Social media</td>
<td>Social media</td>
<td>Social media; Other families; Doctors, therapists, and other medical professionals</td>
<td>Doctors, therapists, and other medical professionals</td>
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<td><strong>Third Choice</strong></td>
<td>Doctors, therapists, and other medical professionals</td>
<td>Doctors, therapists, and other medical professionals</td>
<td>Local/state disability organizations</td>
<td>Research articles or journals</td>
</tr>
</tbody>
</table>
WHAT SOURCES OF INFORMATION OR RESOURCES ABOUT DISABILITY DO YOU FIND MORE HELPFUL?

PROFESSIONALS

<table>
<thead>
<tr>
<th></th>
<th>Educators</th>
<th>State Agencies</th>
<th>Providers</th>
<th>Healthcare</th>
</tr>
</thead>
<tbody>
<tr>
<td>First Choice</td>
<td>Internet searches</td>
<td>Internet searches</td>
<td>Internet searches</td>
<td>Internet searches</td>
</tr>
<tr>
<td>Second Choice</td>
<td>Teachers or other</td>
<td>Staff from state</td>
<td>Local/state disability organizations</td>
<td>Doctors, therapists, and other medical professionals</td>
</tr>
<tr>
<td></td>
<td>school staff</td>
<td>agencies or programs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Third Choice</td>
<td>Conferences or</td>
<td>Conferences or</td>
<td>Conferences or</td>
<td>Research articles or journals</td>
</tr>
<tr>
<td></td>
<td>workshops</td>
<td>workshops</td>
<td>workshops</td>
<td></td>
</tr>
</tbody>
</table>

OUR QUESTIONS

1. What **experiences** are most important to individuals with disabilities and their families?

2. How **familiar** are individuals, families, and professionals with disability-related programs and services in their community?

3. How do they characterize their **experiences** trying to locate needed information and services?

4. What are their **primary sources** for disability-related information?

5. What are their **recommendations** for new resources to address these concerns?

6. How do the responses to Q1-Q5 vary based on disability type, participant demographics, geographic locale, and stakeholder role?
**HOW LIKELY WOULD YOU BE TO USE EACH OF THE FOLLOWING RESOURCES IF IT WAS AVAILABLE?**

<table>
<thead>
<tr>
<th>Resource</th>
<th>Individuals with Disabilities</th>
<th>Parents and Families</th>
<th>Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>A website where you can search for resources</td>
<td>55%</td>
<td>36%</td>
<td>32%</td>
</tr>
<tr>
<td>An app on your smartphone</td>
<td>42%</td>
<td>38%</td>
<td>38%</td>
</tr>
<tr>
<td>A live chat feature where you can ask questions in real time</td>
<td>32%</td>
<td>41%</td>
<td>18%</td>
</tr>
<tr>
<td>Notifications based on disability, age, and community</td>
<td>31%</td>
<td>40%</td>
<td>14%</td>
</tr>
<tr>
<td>Notifications of upcoming or local events</td>
<td>26%</td>
<td>43%</td>
<td>23%</td>
</tr>
<tr>
<td>A printed guide that explains disability resources</td>
<td>29%</td>
<td>39%</td>
<td>26%</td>
</tr>
<tr>
<td>Ratings and reviews of resources from others</td>
<td>26%</td>
<td>42%</td>
<td>28%</td>
</tr>
<tr>
<td>A toll free phone number where you can talk directly to someone</td>
<td>27%</td>
<td>26%</td>
<td>29%</td>
</tr>
<tr>
<td>A Facebook page that provides information about services</td>
<td>27%</td>
<td>37%</td>
<td>16%</td>
</tr>
<tr>
<td>A weekly or monthly e-newsletter highlighting resources</td>
<td>27%</td>
<td>48%</td>
<td>14%</td>
</tr>
<tr>
<td>A print newsletter highlighting resources</td>
<td>11%</td>
<td>36%</td>
<td>3%</td>
</tr>
<tr>
<td>Online videos that explain what various programs offer</td>
<td>24%</td>
<td>47%</td>
<td>7%</td>
</tr>
<tr>
<td>Text messages about resources</td>
<td>27%</td>
<td>41%</td>
<td>28%</td>
</tr>
<tr>
<td>A podcast that talks about disability resources or topics</td>
<td>23%</td>
<td>41%</td>
<td>16%</td>
</tr>
</tbody>
</table>

**Most Likely to Use**

<table>
<thead>
<tr>
<th>Most Likely to Use</th>
<th>Individuals with Disabilities</th>
<th>Families</th>
<th>Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>First</strong></td>
<td>Website where you can search for resources (91%)</td>
<td>Website where you can search for resources (91%)</td>
<td>Website where you can search for resources (98%)</td>
</tr>
<tr>
<td><strong>Second</strong></td>
<td>An app on your smartphone (80%)</td>
<td>An app on your smartphone (78%)</td>
<td>Notifications based on disability, age, &amp; community (81%)</td>
</tr>
<tr>
<td><strong>Third</strong></td>
<td>Notifications based on disability, age, &amp; community (79%)</td>
<td>Ratings and reviews of resources from others (76%)</td>
<td>A printed guide that explains disability resources (80%)</td>
</tr>
</tbody>
</table>
HOW LIKELY WOULD YOU BE TO USE EACH OF THE FOLLOWING RESOURCES IF IT WAS AVAILABLE?

<table>
<thead>
<tr>
<th>Less Likely to Use</th>
<th>Individuals with Disabilities</th>
<th>Families</th>
<th>Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>First</strong></td>
<td>A print newsletter highlighting resources (49%)</td>
<td>A podcast that talks about disability resources or topics (48%)</td>
<td>Text messages about resources (43%)</td>
</tr>
<tr>
<td><strong>Second</strong></td>
<td>Text messages about resources (55%)</td>
<td>Text messages about resources (55%)</td>
<td>A podcast that talks about disability resources or topics (48%)</td>
</tr>
<tr>
<td><strong>Third</strong></td>
<td>A toll-free phone number where you can talk directly to someone (60%)</td>
<td>A print newsletter highlighting resources (61%)</td>
<td>A Facebook page that provides information about services (62%)</td>
</tr>
</tbody>
</table>

Contact Information

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