

TENNESSEE DISABILITY SERVICES STUDY REPORT



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PEABODY COLLEGE

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Supporting Tennesseans with disabilities and their families to flourish in all aspects of their lives is central to the collective work of disability agencies, organizations, programs, and schools. The formal and informal services and programs available across this state are critical to ensuring the needs of people with disabilities and their families are met. Yet so many are unaware of—or still struggle to locate—the disability-related information, resources, training, and support they need. Likewise, many professionals (e.g., educators, healthcare workers, state agency staff) working in the area of disability are themselves uncertain of who else in their community could be drawn upon as partners. Navigating the maze of information sources and disability service systems is often described as difficult and discouraging.

In Fall 2021, the *Tennessee Council on Developmental Disabilities* funded a one-year evaluation project to examine what matters most to disability and professional communities across the state, to ask how they currently find needed information, and to solicit their recommendations for making this process easier. *Vanderbilt University* has led this project in partnership with the *Vanderbilt Kennedy Center UCEDD*, multiple state agencies, and numerous disability-focused organizations. Over the last year, we have surveyed more than 3,000 individuals with disabilities, family members, educators, providers, agency staff, and healthcare workers to address a series of key questions:

- What are the most pressing needs and questions of Tennesseans?
- Where are they turning for information and resources?
- What are their most insightful recommendations for improving this process?
- How do these answers vary based on who is asked, what they do, and where in the state they live?

In addition, we held 26 focus groups with a selection of more than 100 stakeholders to obtain in-depth feedback on each of these questions.

All of this information is being used to inform the ongoing work of *Tennessee Disability Pathfinder* (<https://www.tnpathfinder.org/>), the state's central informational and referral program dedicated to helping people with disabilities, their families, and professionals find and access resources and services. It is also useful information for the numerous state agencies, disability organizations, and schools in Tennessee who are also trying to connect people with disabilities and their families to needed information and resources.

This report provides an in-depth look at the insights shared by so many different people from across our state. It also offers practical recommendations for addressing enduring needs related to accessing information and services that enable people with disabilities to flourish. It can be used by state agencies and organizations as they reflect on their own service delivery and dissemination efforts.

OUR APPROACH

We used a mixed-method approach to carry out this statewide evaluation. We combined quantitative data obtained through surveys and qualitative data obtained through focus groups. Each approach is described briefly below.

Statewide Survey. We worked closely with representatives of the *Tennessee Council on Developmental Disabilities* and *Tennessee Disability Pathfinder* to develop a survey that addressed key topics related to accessing information and resources. We also reviewed the relevant literature and received feedback from a core leadership team representing multiple state agencies. The survey could be completed online in English or Spanish; print copies were also available by request.

We sought input from eight primary stakeholder groups: individuals with disabilities, parents, siblings, other loved ones, educators, disability providers, state agency staff, and healthcare workers. Different versions of the survey were tailored to these groups. While each survey addressed a common set of questions, the wording and items varied somewhat across versions. These sections included:

- Personal, family, professional, and community demographics
- Experiences that are important to individuals with disabilities
- Knowledge of disability-related programs and services in the community
- Experiences locating needed information and services
- Preferred sources of disability information
- Experiences using Tennessee Disability Pathfinder
- Recommendations for new resources

Most survey items were rated using Likert-type scales. However, we also included multiple open-ended questions that allowed participants to elaborate on their responses.

The survey remained open for six months, from December 2020 to April 2021. To encourage high participation, we offered \$20 gift cards to 100 randomly selected people who completed the survey. We also provided space for participants to request free resources that might be helpful to them or the individuals they support. We estimate that each survey took 20-30 minutes to complete. Our recruitment efforts are described in the next section.

Stakeholder Focus Groups. We invited a subset of survey participants to also take part in follow-up focus groups. The purpose of these extended interviews was to gather more in-depth information about people's experiences, challenges, and recommendations related to accessing needed disability information and resources. We asked multiple questions addressing the following areas:

- Their experiences finding information and resources for themselves
- Their experiences connecting individuals with disabilities and families to resources
- The sources of information they rely on and trust
- Their recommendations for strengthening information dissemination in our state
- How the struggle to access information and resources impacts their lives

As with the surveys, we worded the questions slightly different for each stakeholder group.

The focus groups were organized by stakeholder group (e.g., parents, educators) and involved 2-7 people. A member of our project team facilitated the conversation using a semi-structured interview protocol. Focus groups were held on Zoom, a secure web-based videoconferencing platform. They lasted between 41 and 117 minutes ($M = 71$ min). We provided \$25 gift cards to every person who participated. The audio recordings for each focus group were transcribed, double-checked, and de-identified before beginning our analyses.

WHOSE PERSPECTIVES ARE REPRESENTED IN THIS REPORT?

A total of 3,042 participants submitted a completed survey. This includes 726 individuals with disabilities, 1,081 parents, 73 siblings, 63 loved ones, 504 educators, 212 state agency staff, 294 disability providers, and 89 healthcare workers. To be part of the study, participants had to have been at least 18 years-old and lived or worked in Tennessee. Table A1 outlines additional inclusion criteria for each group.

Our recruitment plan was designed to reach as many Tennesseans as possible and build a survey sample that is representative of the state's diverse population. Examples of partner organizations and recruitment methods are listed in Table A1. To start, we developed a list of organizations, networks, and programs that had connections with the eight stakeholder groups. We asked these organizations to distribute study invitations by email, in electronic or print newsletters, by posting on their website, and through social media. In addition, we ran advertisements on Facebook.

Stakeholder Group	Inclusion Criteria	Example Recruitment Partners and Methods
Individuals with Disabilities	<ul style="list-style-type: none"> • Have a disability 	<ul style="list-style-type: none"> • College or university disability services offices • American Sign Language interpreting services • Recreational programs (e.g., Special Olympics)
Parents	<ul style="list-style-type: none"> • Be a parent, guardian, or conservator of someone with a disability 	<ul style="list-style-type: none"> • The Arc Tennessee and its local chapters • Facebook parent support groups • Advocacy groups • Training and education programs
Siblings	<ul style="list-style-type: none"> • Be a brother or sister of someone with a disability 	<ul style="list-style-type: none"> • Tennessee Adult Brothers and Sisters
Loved Ones	<ul style="list-style-type: none"> • Be a spouse or child of a someone with a disability 	<ul style="list-style-type: none"> • Advocacy groups • Emotional and educational support groups
Educators	<ul style="list-style-type: none"> • Be a professional who works with students with disabilities in a school or college setting (e.g., teacher, related service provider, administrator, professor) 	<ul style="list-style-type: none"> • Public K-12 schools • Private special education schools • Head Start locations • Schools for the blind and schools for the deaf • County boards of education
Providers	<ul style="list-style-type: none"> • Be a professional who works for an organization, program, or non-profit that serves individuals with disabilities or their families 	<ul style="list-style-type: none"> • Disability-specific organizations • Centers for Independent Living • Cultural and community centers • Community libraries and newspapers • Direct service providers
State Agencies	<ul style="list-style-type: none"> • Be a professional who works for a state agency that serves people with disabilities 	<ul style="list-style-type: none"> • Social media posts • Shared with staff and client listservs • Presented at staff meetings
Healthcare Workers	<ul style="list-style-type: none"> • Be a professional who works with individuals with disabilities in a medical or healthcare setting 	<ul style="list-style-type: none"> • Pediatric and medical associations • Pediatricians and pediatric dentists • Children's hospitals • Specialized clinics

DEMOGRAPHIC INFORMATION

The following figures display demographic information for each stakeholder group. We wanted to learn more about the characteristics of each participant, as well as the individuals with disabilities they are related to or work with. Individuals with disabilities, parents, siblings, and loved ones were asked about their own disability or their family member's disability type. Participants were asked questions about themselves, including their race/ethnicity, sex, and community type (see Figures A1-A8). Additional demographic information (e.g., age, marital status, highest level of education) is presented in Appendix A.

Professionals (i.e., educators, state agency staff, providers, and healthcare workers) were asked about the individuals with disabilities they support or work with. For example, they were asked about the communities in which the individuals with disabilities they serve live. Additional questions specific to their role were asked of each group, such as the age-level served and their years of experience (see Appendix A).

Disability Type

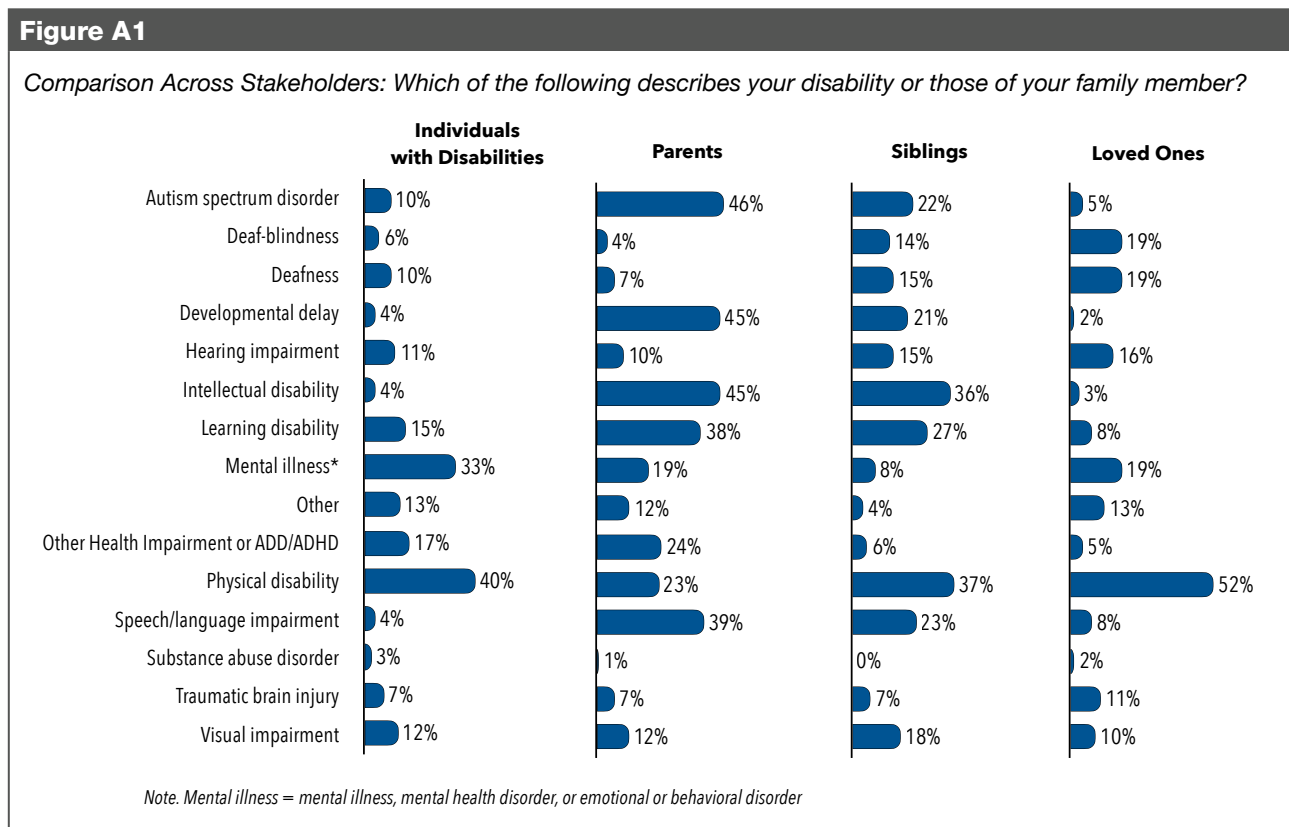
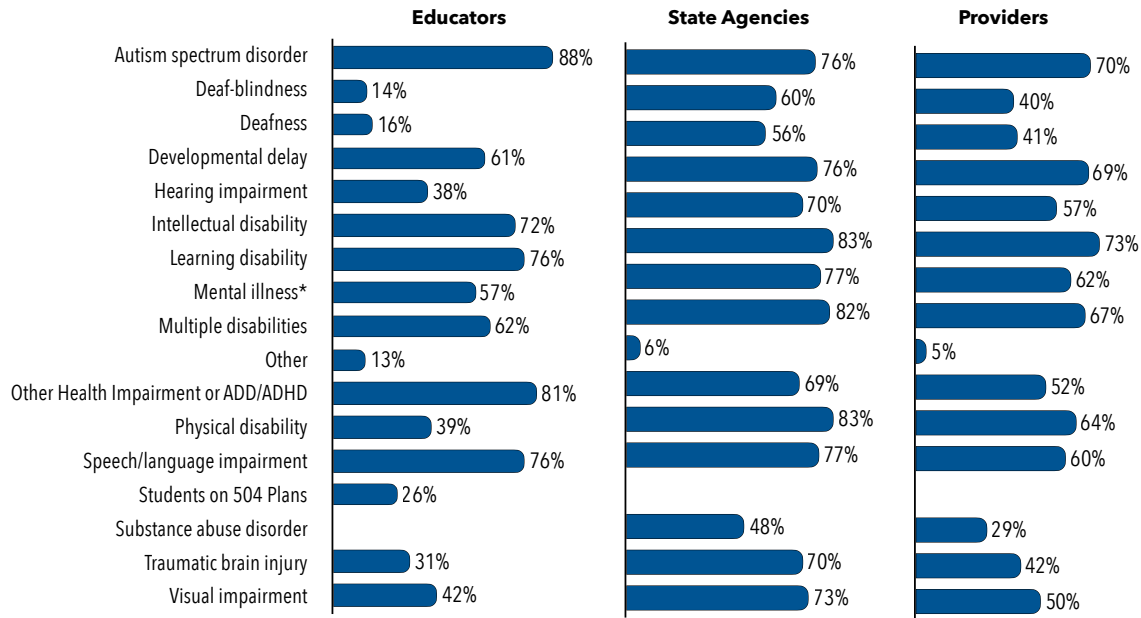


Figure A1 presents the disabilities reported by individuals with disabilities, as well as others who were reporting on their family members. Participants could select more than one disability to describe themselves or their family member; therefore, the total percentages can exceed 100%. Among individuals with disabilities, the most common disabilities were mental health disorder and physical disability. Among parents, the most common disabilities of their children were autism spectrum disorder, intellectual disability and developmental delay. Among siblings and loved ones, the most common disability of their family member was physical disability.

Figure A2

Comparison Across Stakeholders: Which types of disabilities do the individuals you support have?



Note. Mental illness = mental illness, mental health disorder, or emotional or behavioral disorder

Figure A2 displays the disabilities reflected among the individuals that educators, state agency staff, and providers supported. Professionals could select more than one disability; therefore, the total percentages can exceed 100%. The label “students on 504 plans” was available only to educators and “substance abuse disorder” was not listed for educators.

Race/Ethnicity

Figure A3

Comparison Across Stakeholders: What is your race/ethnicity?

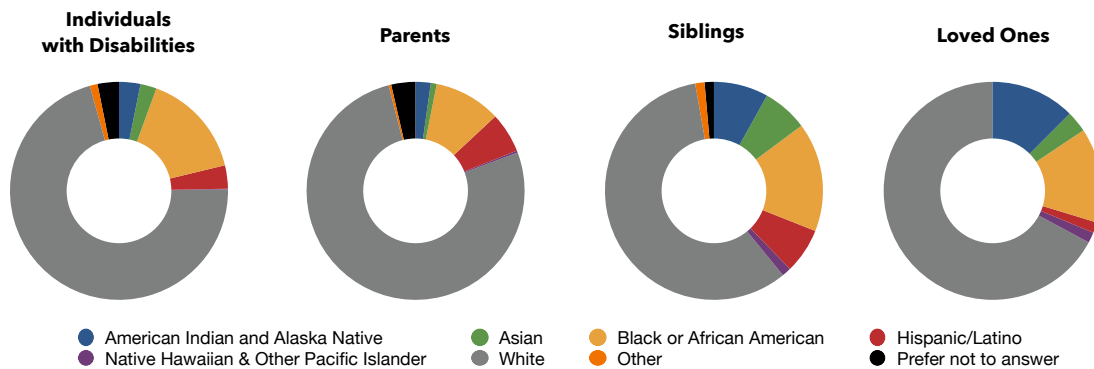


Figure A3 presents the race/ethnicity for individuals with disabilities, parents, siblings, and loved ones.

Figure A4

Comparison Across Stakeholders: What is your race/ethnicity?

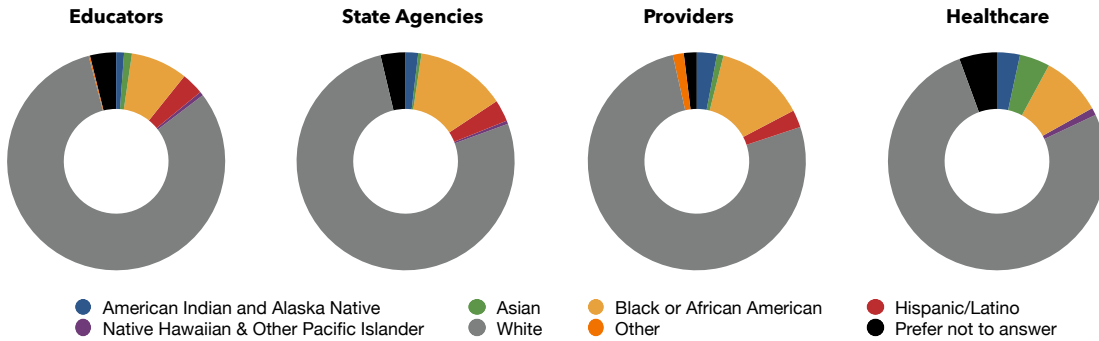


Figure A4 presents the race/ethnicity for educators, state agency staff, providers, and healthcare workers.

Sex

Figure A5

Comparison Across Stakeholders: What is your sex?

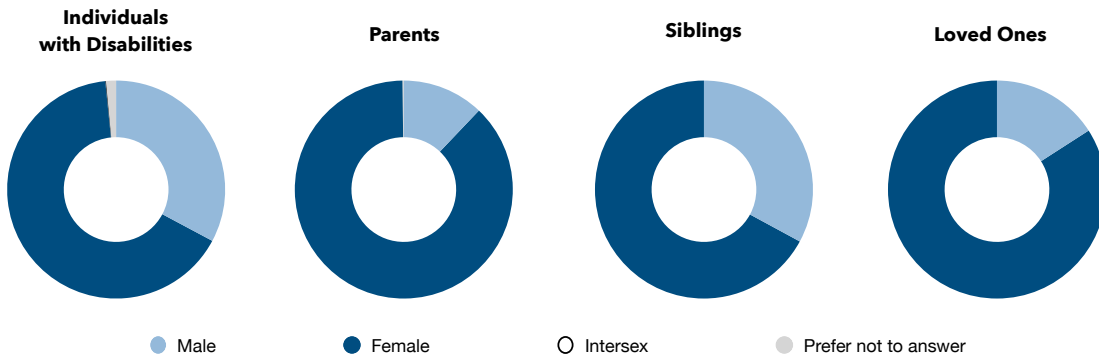


Figure A5 presents the sex of individuals with disabilities, parents, siblings, and loved ones. Most participants in these four groups were female.

Figure A6

Comparison Across Stakeholders: What is your sex?

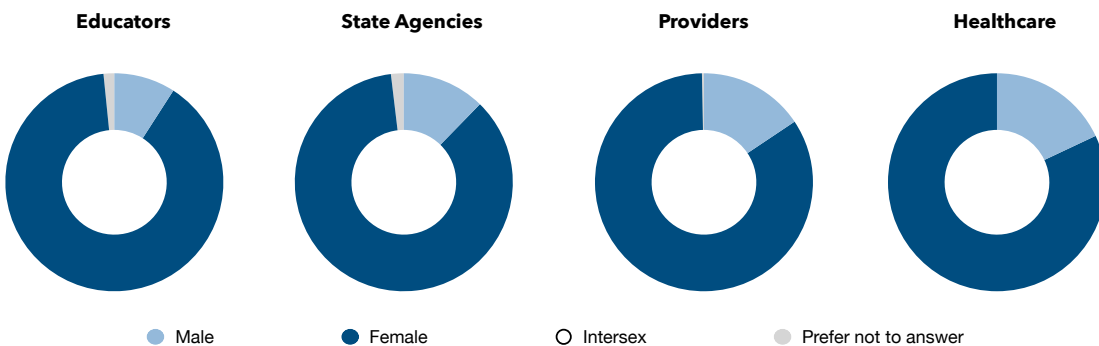


Figure A6 presents the sex of educators, state agency staff, providers, and healthcare workers. Most participants in these four groups were female.

Community Type

Figure A7

Comparison Across Stakeholders: How would you describe your community where you live?

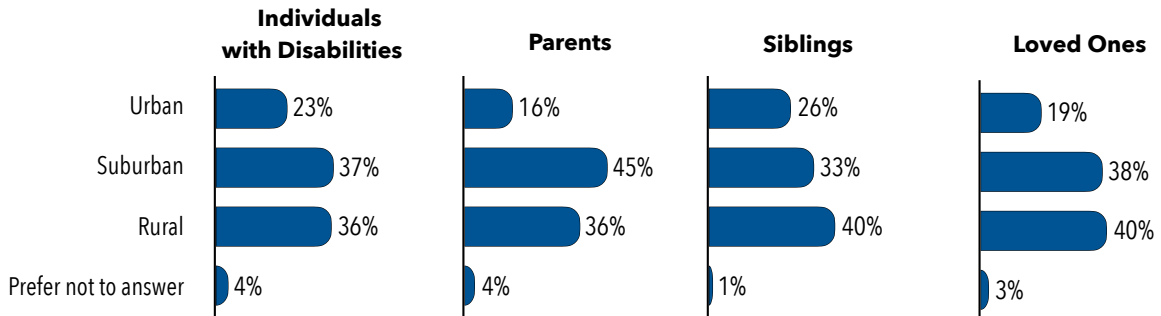


Figure A7 shows the types of communities in which individuals with disabilities, parents, siblings, and loved ones lived. Participants could select from the following communities: *urban*, *suburban*, *rural*, or *prefer not to answer*. The highest percentage of individuals with disabilities and parents live in suburban communities. The highest percentage of siblings and loved ones live in rural communities.

Figure A8

Comparison Across Stakeholders: How would you describe the communities of the individuals with disabilities you serve?

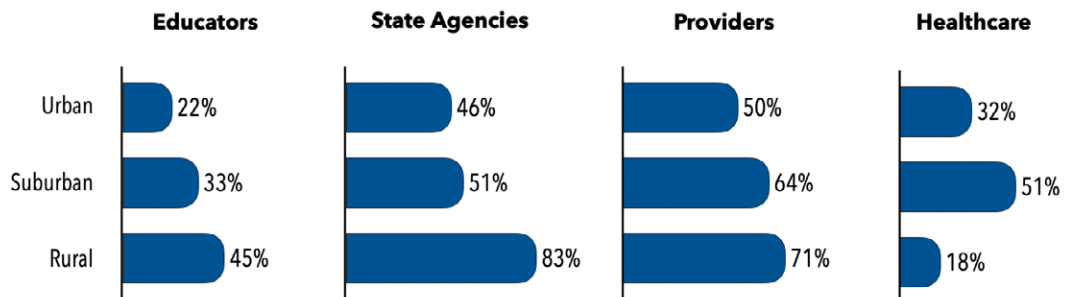


Figure A8 shows the communities served by educators, state agency staff, providers, and healthcare workers. Participants could select the following three options: *urban*, *suburban*, *rural*. Educators and healthcare workers could only select one community type, while state agency staff and providers could select multiple community types.

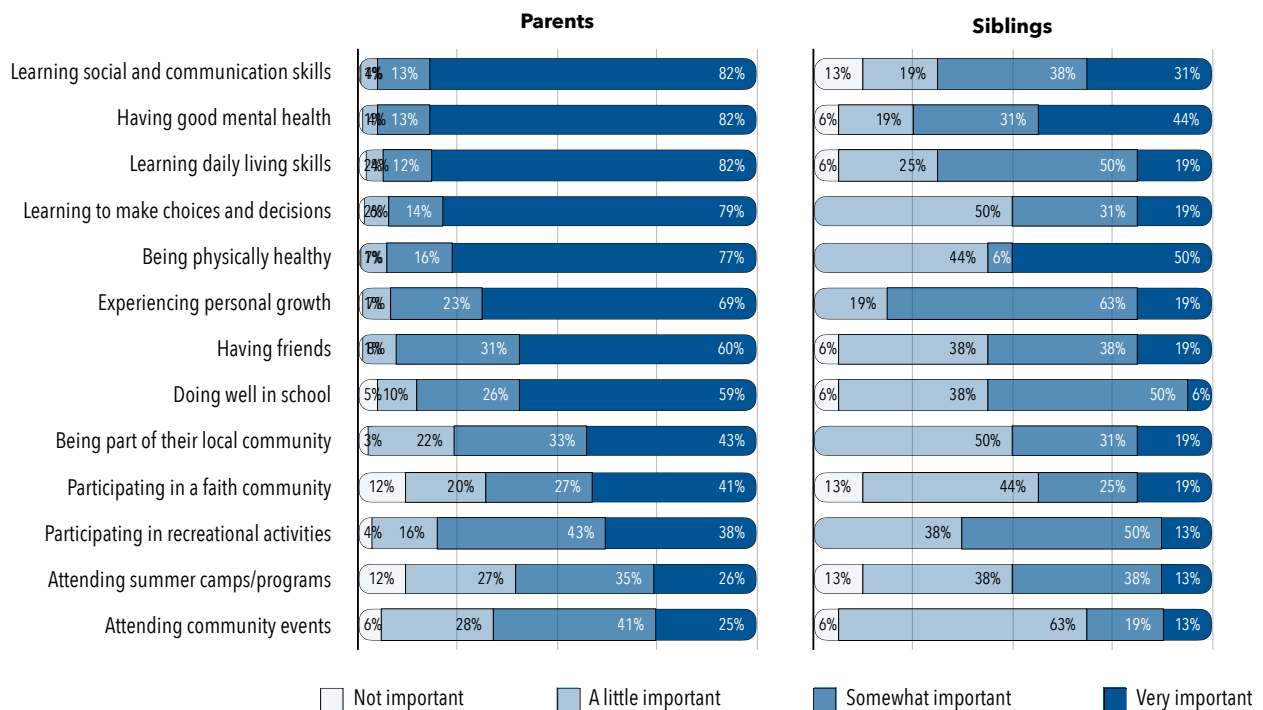
WHAT EXPERIENCES ARE IMPORTANT FOR INDIVIDUALS WITH DISABILITIES?

We wanted to learn more about the experiences that were important to and for people with disabilities across the state. Determining which experiences are valued most highly can help organizations know where resources and information may be especially needed. We asked for input from individuals with disabilities, their parents, and their siblings and loved ones.

The main survey question on this topic read: **How important is each experience for you (or your family member with disabilities)—now or in the future?** We provided a list of various experiences that might be valued by anyone in the community. They could respond with one of four choices: *not important*, *a little important*, *somewhat important*, or *very important*. The list of experiences differed when referencing children with disabilities (ages 12 and under; see Figure B1) versus youth and adults with disabilities (ages 13 and older; see Figure B2).

Figure B1

Comparison Across Stakeholders: How important is each experience for your family member (age 12 and younger) with disabilities—now or in the future?



“Right now, my husband and mostly me are her world. She’s very high functioning, and my goal for her is to be an independent happy adult who can contribute to society and have self-worth. I don’t know how to get there after high school.”

– Parent of an 18-year-old daughter

Views of parents of younger children. All 13 experiences were considered somewhat or very important by the majority of parents of younger children (see Figure B1). The three most valued experiences were:

- Learning social and communication skills (95%)
- Having good mental health (95%)
- Learning daily living skills (94%)

The average number of different experiences they considered somewhat or very important was 10.9.

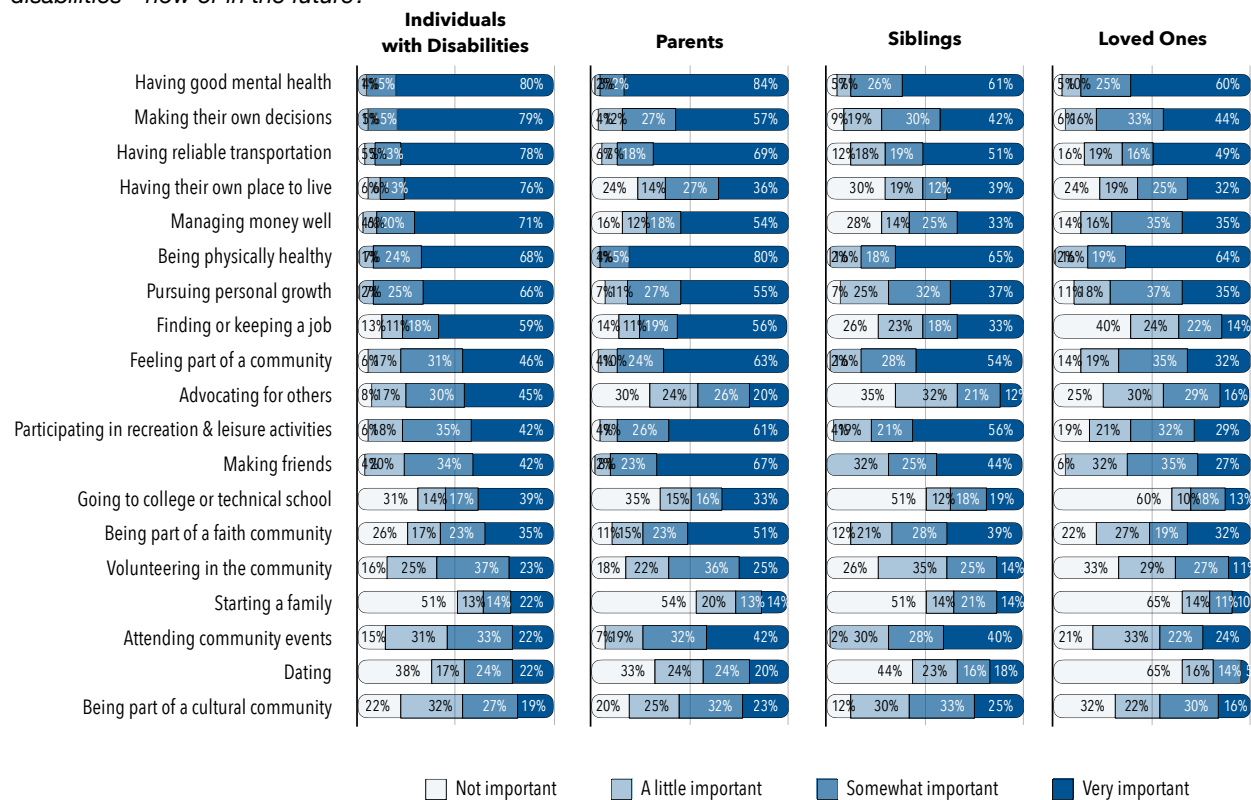
Views of siblings of younger children. Eleven of the 13 experiences were considered somewhat or very important by the majority of siblings of these younger children (see Figure B1). The three most valued experiences were:

- Experiencing personal growth (81%)
- Having good mental health (75%)
- Learning daily living skills (69%)

The average number of different experiences they considered somewhat or very important was 7.5.

Figure B2

Comparison Across Stakeholders: How important is each experience for your family member (age 13 and older) with disabilities—now or in the future?



“Forming meaningful connections with those in her life [is important]. We never want her to just be ‘the mascot’ or the person there for laugh or because *it is the right thing.*”

– Parent of a 12-year-old daughter

Views of individuals with disabilities. All but three of the 19 experiences were considered somewhat or very important by the majority of individuals with disabilities (see Figure B2). The most valued experiences were:

- Having good mental health (95%)
- Making their own decisions (94%)
- Pursuing personal growth (92%)
- Being physically healthy (92%)

The average number of different experiences they considered somewhat or very important was 13.8. Individuals who were more highly educated tended to rate more items as important.

Views of parents of youth and adults. All but four of the 19 experiences were considered somewhat or very important by the majority of parents of youth and adults (see Figure B2). The three most valued experiences were:

- Having good mental health (95%)
- Being physically healthy (95%)
- Making friends (90%)

The average number of different experiences they considered somewhat or very important was 13.4. Parents who were non-White or who were more highly educated tended to rate more items as important.

Views of siblings of youth and adults. All but five of the 19 experiences were considered somewhat or very important by the majority of siblings of youth and adults (see Figure B2). The three most valued experiences were:

- Having good mental health (88%)
- Feeling part of the community (83%)
- Being physically healthy (83%)

The average number of different experiences they considered somewhat or very important was 11.4.

Views of loved ones of youth and adults. All but eight of the 19 experiences were considered somewhat or very important by the majority of loved ones of youth and adults (see Figure B2). The three most valued experiences were:

- Having good mental health (86%)
- Being physically healthy (83%)
- Making their own decisions (78%)

The average number of different experiences they considered somewhat or very important was 10.3. Loved ones of those with intellectual disability and autism spectrum disorder tended to rate more items as important.

Other areas. We also included an open-ended question in which everyone could add other important areas that were not reflected in the lists we provided. Below is a sampling of those responses:

- Being politically active
- Being useful in some way each day
- Continuing services into adulthood
- Developing long-term hobbies
- Feeling understood by employers
- Managing health needs
- Navigating the community
- Owning a pet
- Parenting effectively with a disability
- Practicing good hygiene and self-care
- Using assistive technology

“Having the opportunity to fail at things and learn from my own mistakes.”

– Adult (in her 50s) with multiple disabilities

↘ Key Points and Implications

- » Individuals with disabilities want the same array of experiences that any Tennessean might want—a good job, close friends, good health, a safe place to live, involvement in their community, and much more. These universal aspirations should be honored and supported.
- » Use these data to showcase to state leaders, policymakers, and communities what is important to individuals with disabilities and their families.
- » Physical and mental health were prioritized by all stakeholders and should be strongly supported for all Tennesseans with disabilities.
- » Reflect on whether you are promoting access to the array of experiences prioritized by individuals with disabilities and their families in your midst.
- » Ask individuals and families you serve about the experiences that matter most to them. Almost every person we surveyed shared a unique combination of valued experiences; no two people were exactly alike in their priorities.
- » Ensure resources are available that align with each of the priority areas outlined in this report.

WE CONCLUDE THIS SECTION WITH A SAMPLING OF QUOTES RELATED TO THE IMPORTANCE OF VARIOUS EXPERIENCES:

“Being able to have the same opportunities and options for furthering education and training. To be able to succeed and follow her dreams and goals in life, like any typical child would have.”

– Parent of a 3-year-old daughter

“Finding a purpose...I still grieve for a purpose. I can volunteer, but right now no volunteers are allowed in most places.”

– Adult (in her 40s) with a physical disability and deafness

“The opportunity to recreate—for example, experiencing accessible community parks, nature, museums, and other indoor and outdoor venues.”

– Adult (in their 60s) with a physical disability

“I just want my son to be able to live his life to the fullest. I hope when he’s older...he may be able to experience love and companionship.”

– Parent of an 11-year-old son

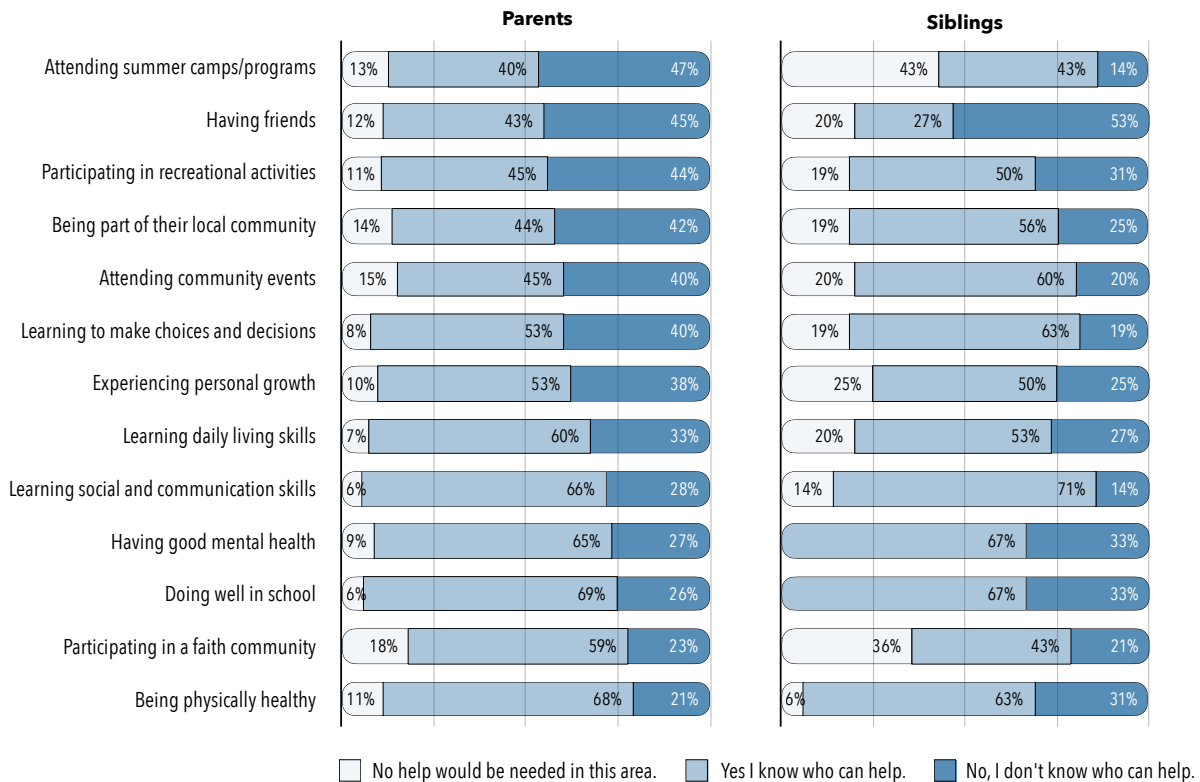
DO PEOPLE KNOW WHO CAN HELP?

We wanted to learn whether individuals with disabilities, their families, and professionals were aware of programs and services in the community that could assist them in various areas of their lives. The more familiar people are with available resources, the more likely they are to have their needs met. We asked for input from all eight stakeholder groups.

After learning about each of the experiences individuals and families considered to be important, we wanted to know whether they were aware of resources related to each of those valued experiences. The survey question read: **Do you know of programs or services in your community that could help you (or your family member) in each area—either now or in the future?** Participants were only presented experiences from the prior section that they rated as somewhat important or very important. They could respond with one of three choices: *No help would be needed in this area*; *Yes, I know how can help*; and *No, I don't know who could help*. The list of experiences differed when referencing children with disabilities (ages 12 and under; see Figure C1) versus youth and adults with disabilities (ages 13 and older; see Figure C3).

Figure C1

Comparison Across Stakeholders: Do you know of programs or services in your community that could help your family member (age 12 and under) with disabilities in each area—either now or in the future?



Views of parents of younger children. The three areas in which the most parents were unsure of who could help were (see Figure C1):

- Attending summer camps/programs (47%)
- Having friends (45%)
- Participating in recreational activities (44%)

The average number of areas in which parents said they did not know where to find help was 4.4 of 13. Parents of children with autism spectrum disorder tended to be unsure about more areas.

Views of siblings of younger children. The three areas in which the most siblings were unsure of who could help were (see Figure C1):

- Having friends (53%)
- Having good mental health (33%)
- Doing well in school (33%)

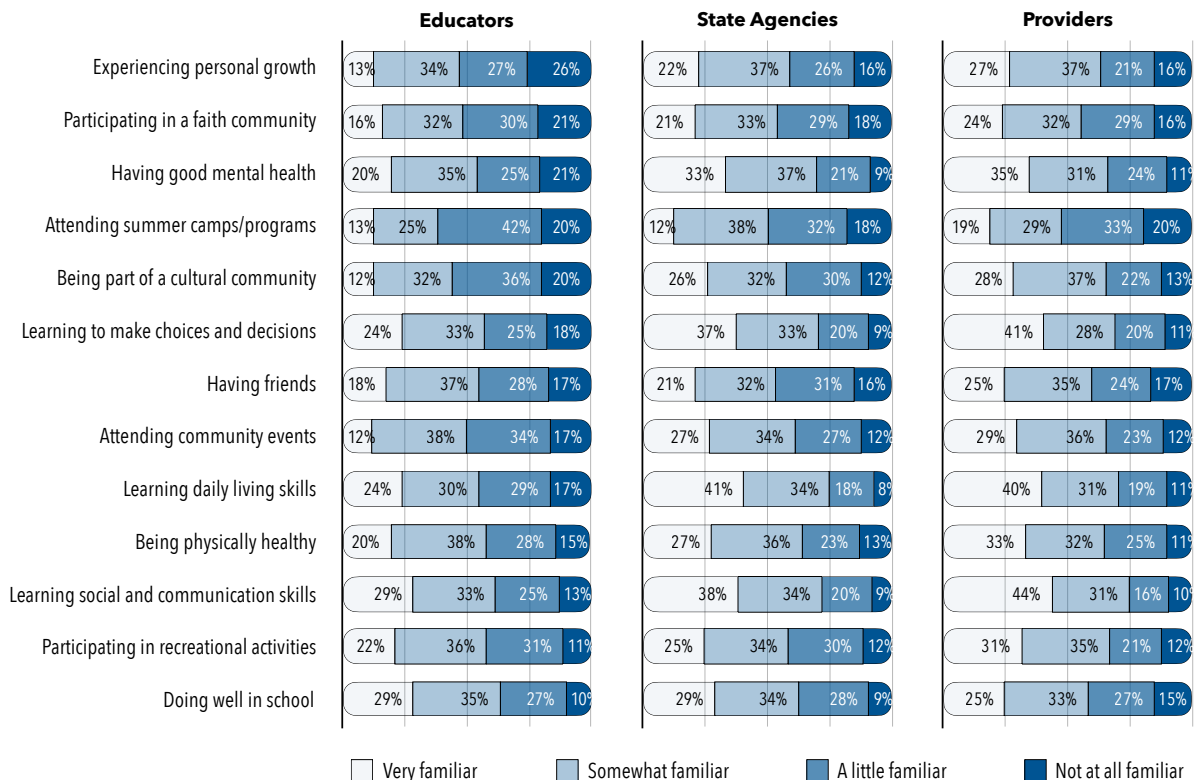
The average number of areas in which siblings said they did not know where to find help was 3.3 of 13.

We also wanted to know whether educators, state agency staff, and providers were familiar with resources for experiences they identified as important. Their awareness of relevant resources impacts the support provided to individuals with disabilities and their families. The survey question for professionals read:

How familiar are you with community programs and services that could help in each area? They could respond with one of four choices: *not at all familiar*, *a little familiar*, *somewhat familiar*, or *very familiar*. The list of experiences differed when referencing children with disabilities (ages 12 and under; see Figure C2) versus youth and adults with disabilities (ages 13 and older; see Figure C4).

Figure C2

Comparison Across Stakeholders: How familiar are you with community programs and services that could help children with disabilities (age 12 and under) in each area?



Views of educators working with younger children. The three areas in which the most educators were only a little familiar or not at all familiar with resources were (see Figure C2):

- Attending summer camps/program (62%)
- Being part of a cultural community (56%)
- Experiencing personal growth (53%)

The average number of areas in which educators were only a little familiar or not at all familiar with resources was 6.1 of 13.

Views of state agency staff supporting younger children. The three areas in which the most state agency staff were only a little familiar or not at all familiar with resources were (see Figure C2):

- Attending summer camps/programs (50%)
- Having friends (47%)
- Participating in a faith community (46%)

The average number of areas in which state agency staff were only a little familiar or not at all familiar with resources was 4.9 of 13.

Views of providers supporting younger children. The three areas in which the most providers were only a little familiar or not at all familiar with resources were (see Figure C2):

- Attending summer camps and programs (52%)
- Participating in a faith community (45%)
- Doing well in school (42%)

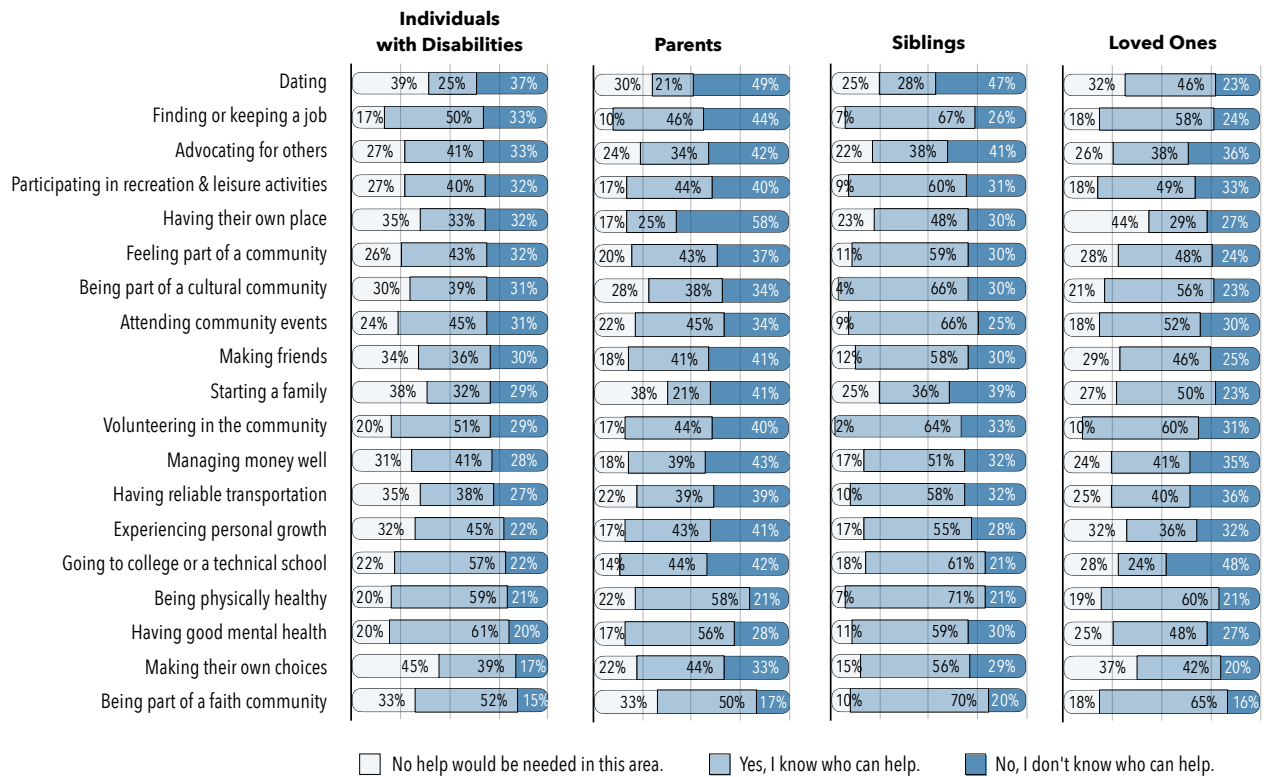
The average number of areas in which providers were only a little familiar or not at all familiar with resources was 4.8 of 13. Providers who did not work with individuals with intellectual disability or autism spectrum disorder tended to have less familiarity with more areas.

“I think just the lack of availability of the resources. You can’t connect parents and individuals with things that aren’t there.”

– Educator with 20 years of experience

Figure C3

Comparison Across Stakeholders: Do you know of programs or services in your community that could help you or your family member (age 13 and up) with disabilities in each area-either now or in the future?



Views of individuals with disabilities. The three areas in which the most individuals with disabilities were unsure of who could help were (see Figure C3):

- Dating (37%)
- Finding or keeping a job (33%)
- Advocating for others (33%)

The average number of areas in which they said they did not know where to find help was 4.5 of 19. Individuals with mental health conditions tended to be less familiar with more areas.

Views of parents of youth and adults. The three areas in which the most parents of youth and adults were unsure of who could help were (see Figure C3):

- Having their own place to live (58%)
- Dating (49%)
- Finding or keeping a job (44%)

The average number of areas in which they said they did not know where to find help was 6.1 of 19. Parents whose family members had autism spectrum disorder tended to be unsure about more areas.

“The lack of services; families are literally suffering. They’re suffering. They’re being torn apart. And not only are the families suffering, but the individual is suffering as well because they see mom and dad getting frustrated.”

– Parent of a 16-year-old son

Views of siblings of youth and adults. The three areas in which the most siblings were unsure of who could help were (see Figure C3):

- Dating (47%)
- Advocating for others (41%)
- Starting a family (39%)

The average number of areas in which they said they did not know where to find help was 4.6 of 19. Siblings whose family members had autism spectrum disorder tended to be unsure about more areas.

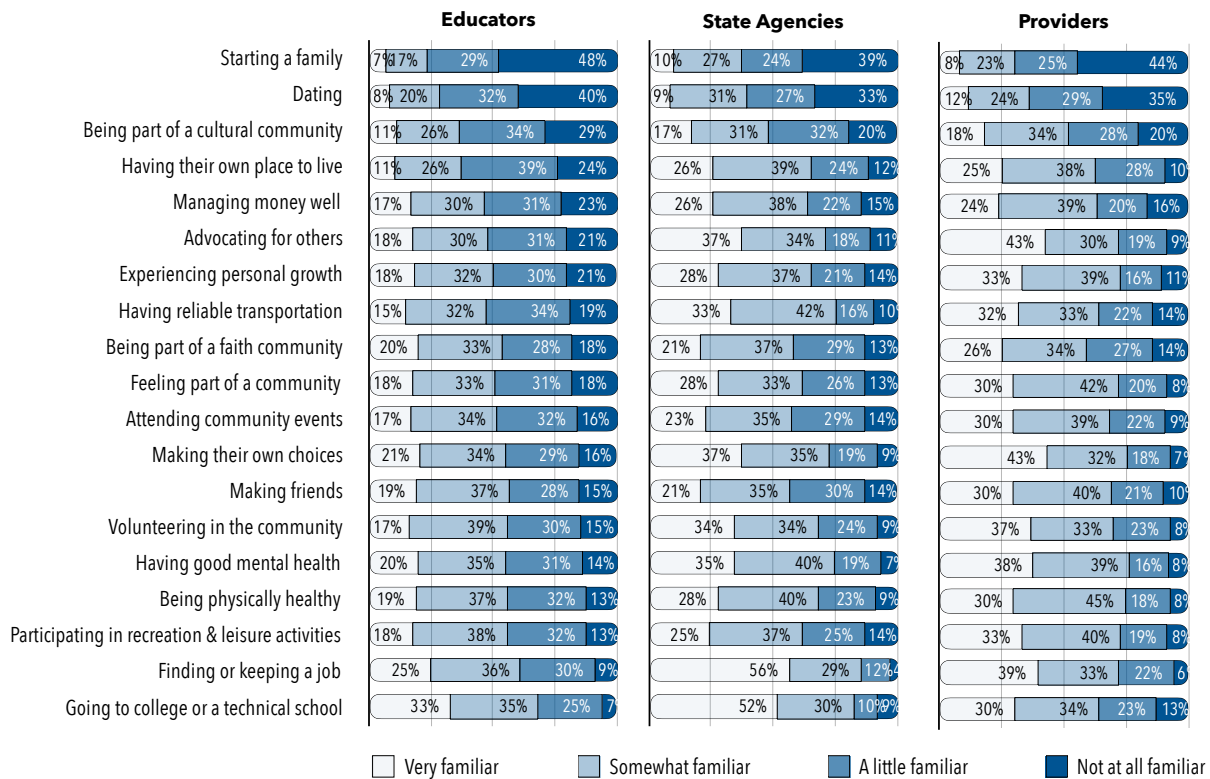
Views of loved ones of youth and adult. The three areas in which the most loved ones were unsure of who could help were (see Figure C3):

- Going to college or technical school (48%)
- Advocating for others (36%)
- Having reliable transportation (36%)

The average number of areas in which they said they did not know where to find help was 4.0 of 19.

Figure C4

Comparison Across Stakeholders: How familiar are you with community programs and services that could help youth and adults with disabilities (age 13 and up) in each area?



Views of educators working with youth and young adults. The three areas in which the most educators were only a little familiar or not at all familiar with resources were (see Figure C4):

- Starting a family (77%)
- Dating (72%)
- Being part of a cultural community (63%)

The average number of areas in which educators were only a little familiar or not at all familiar with resources was 9.7 of 19. Educators with less experience tended to have slightly less familiarity with more items.

Views of state agency staff supporting youth and adults. The three areas in which the most state agency staff were only a little familiar or not at all familiar with resources were (see Figure C4):

- Starting a family (63%)
- Dating (60%)
- Being part of a cultural community (52%)

The average number of areas in which state agency staff were only a little familiar or not at all familiar with resources was 6.9 of 19. Staff with less experience tended to have slightly less familiarity with more items.

Views of providers supporting youth and adults. The three areas in which the most providers were only a little familiar or not at all familiar with resources were (see Figure C4):

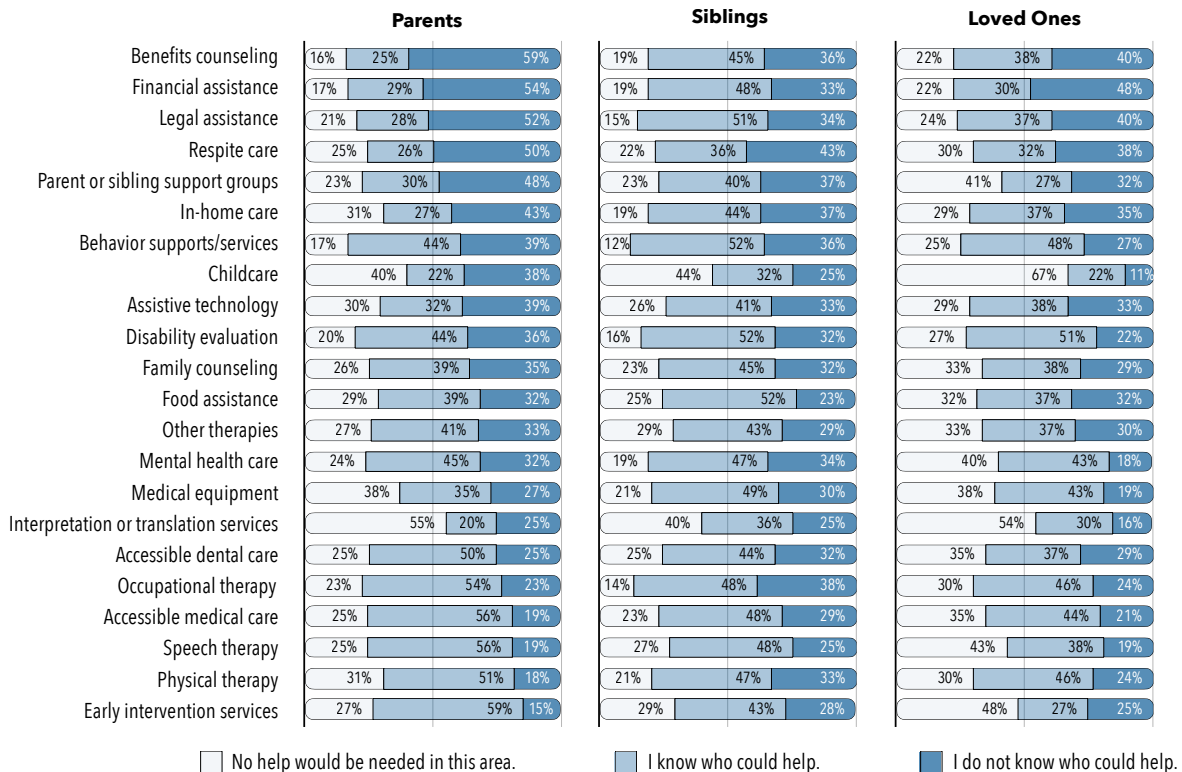
- Starting a family (69%)
- Dating (64%)
- Being part of a cultural community (48%)

The average number of areas in which providers were only a little familiar or not at all familiar with resources was 6.7 of 19. Providers who did not work with individuals with intellectual disability or autism spectrum disorder tended to have less familiarity with more areas. Likewise, those with less experience tended to have slightly less familiarity with more items.

Additionally, we asked parents, siblings, and loved ones to identify whether they knew who could help in 22 other areas in which families often seek assistance. Our question was worded: **How familiar are you with community programs and services that could help in each area?** They could respond with one of three choices: *No help would be needed in this area, I know who could help, or I do not know who could help.* Parents, siblings, and loved ones were shown the same list of programs and services (see Figure C5).

Figure C5

Comparison Across Stakeholders: How familiar are you with programs and services in your community that could help in each area?



Views of all parents. The three areas in which the most parents were unsure of who could help were (see Figure C5):

- Benefits counseling (59%)
- Financial assistance (54%)
- Legal assistance (52%)

The average number of areas in which all parents were unsure of who could help was 7.5 of 22.

Views of all siblings. The three areas in which the most siblings were unsure of who could help were (see Figure C5):

- Respite care (43%)
- Occupational therapy (38%)
- Parents or sibling support groups (37%)
- In-home care (37%)

The average number of areas in which all siblings were unsure of who could help was 7.0 of 22.

Views of all loved ones. The three areas in which the most loved ones were unsure of who could help were (see Figure C5):

- Financial assistance (48%)
- Benefits counseling (40%)
- Legal assistance (40%)

The average number of areas in which the most loved ones were unsure of who could help was 6.1 of 22.

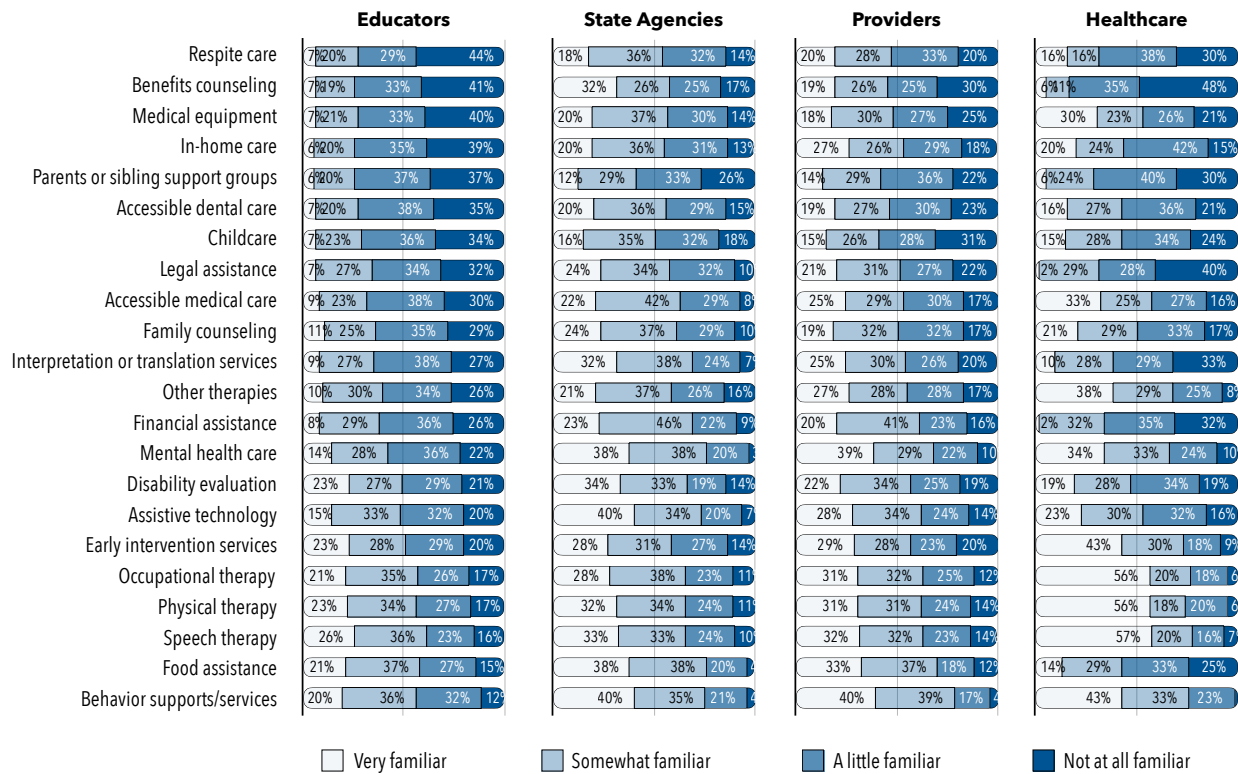
Educators, state agency staff, and providers were asked about their familiarity with resources in the same 22 areas. They could respond with one of four choices: *not at all familiar*, *a little familiar*, *somewhat familiar*, or *very familiar*. Professionals were shown the same list of programs and services (see Figure C6). Healthcare workers were asked about five additional areas: educational services, residential services, recreational and leisure programs, vocational services, and social supports (see Figure C7).

“I am thankful for the programs that are there in the state of Tennessee and extremely thankful that we’ve been able to take advantage of them. But a lot of people haven’t!”

– Parent of a 25-year-old son

Figure C6

Comparison Across Stakeholders: How familiar are you with programs and services in your community that could help in each area?



Views of all educators. The three areas in which the most educators were only a little familiar or not at all familiar with resources were (see Figure C6):

- Benefits counseling (75%)
- Parents or sibling support groups (74%)
- In-home care (74%)

The average number of areas in which educators were only a little familiar or not at all familiar with resources was 13.2 of 22.

Views of all state agency staff. The three areas in which the most state agency staff were only a little familiar or not at all familiar with resources were (see Figure C6):

- Parents or sibling support groups (59%)
- Childcare (50%)
- Respite care (46%)

The average number of areas in which state agency staff were only a little familiar or not at all familiar with resources was 8.3 of 22.

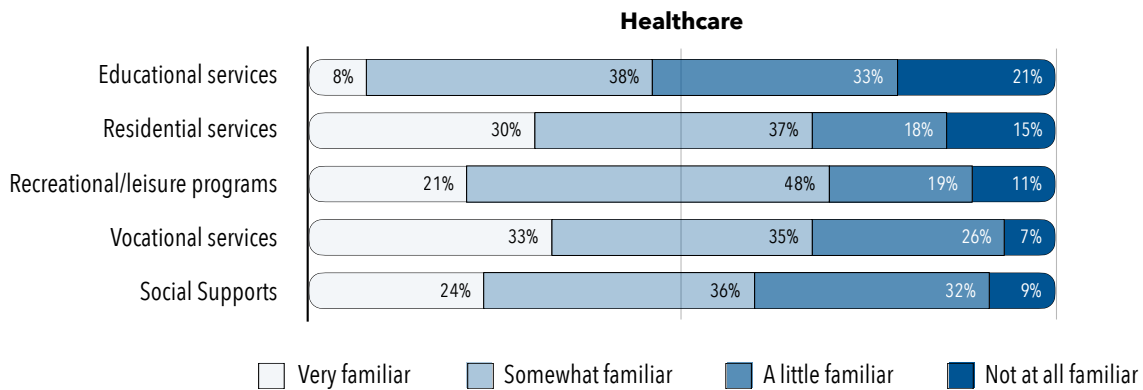
Views of all providers. The three areas in which the most providers were only a little familiar or not at all familiar with resources were (see Figure C6):

- Childcare (59%)
- Parents or sibling support groups (58%)
- Benefits counseling (54%)

The average number of areas in which providers were only a little familiar or not at all familiar with resources was 9.7 of 22.

Figure C7

Comparison Across Stakeholders: How familiar are you with programs and services in your community that could help in each area?



Views of all healthcare workers. The three areas in which the most healthcare workers were only a little familiar or not at all familiar with resources were (see Figure C7):

- Benefits counseling (83%)
- Parents or sibling support groups (71%)
- Respite care (69%)
- Legal assistance (69%)

The average number of areas in which healthcare workers were only a little familiar or not at all familiar with resources was 13.9 of 22.

Key Points and Implications

- » There are many areas in which individuals with disabilities and their families are uncertain about where to find help. In most areas, between one-fifth and one-half of people did not know where to turn for information or resources.
- » Likewise, large numbers of professionals also noted areas in which they had limited familiarity with relevant resources.
- » Promoting awareness and use of *Tennessee Disability Pathfinder* can provide one way of connecting Tennesseans to the resources they need in the areas named in this section. Schools, state agencies, and disability organizations should showcase links to *Pathfinder* on their websites and in their materials.
- » Because professionals are often key sources of information for individuals with disabilities and families in local communities, state agencies should consider how to ensure their staff and contractors are familiar with the most salient resources.
- » State agencies and programs should communicate about their available and planned resources to ensure coverage is available of all of the topic areas outlined in this report.
- » Resources should be provided in multiple languages to address the growing number of Tennesseans who do not speak English as a primary language.
- » Some groups tend to experience more difficulties learning about needed resources, as evident throughout this section. Particular attention should be directed toward ensuring these groups are connected to resources and services.

WE CONCLUDE THIS SECTION WITH A SAMPLING OF QUOTES
FROM OUR FOCUS GROUPS THAT RELATE TO THIS
AREA OF ACCESS TO SERVICES AND SUPPORTS:

“They’re looking for behavioral health providers that serve people with intellectual disability. You know, you could spend years looking for that. And it’s really mentally draining! There are people who live in crisis all the time, so it can be really, really bad, a huge impact, devastating impact to people who are looking and don’t know where to turn.”

– Provider with 4 years of experience

“Transportation. That’s the biggest challenge. We have opportunities that are available, but it’s either like a two- or three-day request that you have to put in. And then its priority is usually to take them to doctor’s appointments, not necessarily job interviews or work shifts. And then the bus here doesn’t run on Sundays. So, it’s just transportation is the biggest challenge.”

– Provider with 3 years of experience

“In my county, if [providers] know about it, they share it. So, if it’s there, yes, they’re great at giving the information. But if they don’t know about it, you don’t know what you don’t know.”

– Parent of a 19-year-old son

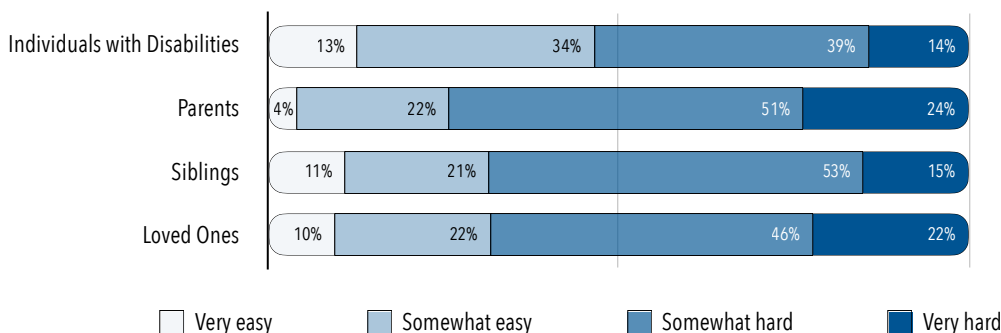
HOW DO TENNESSEANS DESCRIBE THEIR EXPERIENCES FINDING INFORMATION AND SERVICES?

We were interested in learning about people’s experiences—both positive and negative—when looking for disability-related information or services. All stakeholder groups were asked about their experiences in this area. We wanted to know what they found to be easy or challenging, and why. The pursuit of resources was a difficult task for most people. However, some important differences are evident across groups.

The first question in this section asked: **Overall, how easy is it for you to find the information you or your family member with a disability needs?** This was asked of individuals with disabilities, parents, loved ones, and siblings (see Figure D1). The wording was altered slightly for each group. For example, the wording “child(ren) with disabilities” was only used with participants who previously identified their role as a parent. Likewise, the wording “sibling with a disability” was used for brothers and sisters. All participants could respond with one of four choices: *very easy*, *somewhat easy*, *somewhat hard*, or *very hard*.

Figure D1

Comparison Across Stakeholders: Overall, how easy is it for you to find the information you or your family member with a disability needs?



Views of individual with disabilities. Just over half (53%) of individuals with disabilities reported that it was very hard or somewhat hard to find the information they needed (see Figure D1). Less than half (47%) said it was somewhat easy or very easy. Individuals with mental health conditions tended to report that finding information was more difficult.

Views of parents. A large majority (74%) of parents reported that it was very hard or somewhat hard to find the information their family member with a disability needed (see Figure D1). Only one-quarter (26%) said it was somewhat easy or very easy. Parents of children with autism spectrum disorder and those living in rural or suburban communities tended to report that finding information was more difficult.

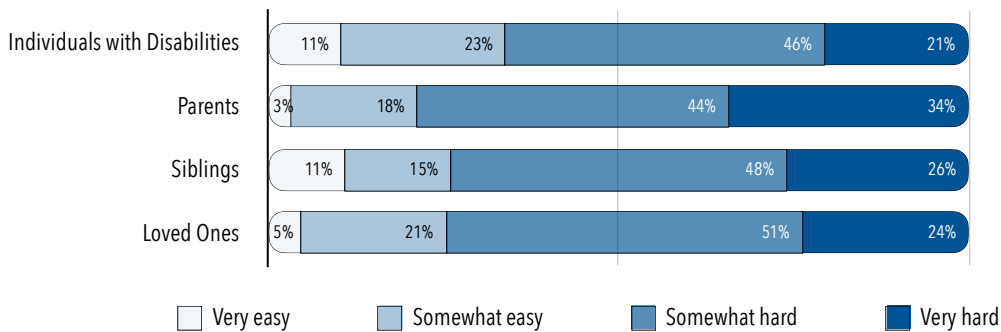
Views of siblings. Two-thirds (69%) of siblings reported that it was very hard or somewhat hard to find the information their family member with a disability needed (see Figure D1). Only one-third (32%) said it was somewhat easy or very easy.

Views of loved ones. Two-thirds (68%) of loved ones reported that it was very hard or somewhat hard to find the information their family member with a disability needed (see Figure D1). Only one-third (32%) said it was somewhat easy or very easy.

The second question in this section asked: **Overall, how easy is it for you to find the help you or your family member with a disability needs?** This was asked of individuals with disabilities, parents, loved ones, and siblings (see Figure D2). All participants could respond with one of four choices: *very easy*, *somewhat easy*, *somewhat hard*, or *very hard*.

Figure D2

Comparison Across Stakeholders: Overall, how easy is it for you to find the help you or your family member with a disability needs?



Views of individual with disabilities. Two-thirds (66%) of individuals with disabilities reported that it was very hard or somewhat hard to find the help they needed (see Figure D2). Only one-third (34%) said it was somewhat easy or very easy (34%). Individuals with mental health conditions tended to report that finding help was more difficult.

Views of parents. More than three-quarters (79%) of parents reported that it was very hard or somewhat hard to find the help their family member with a disability needed (see Figure D2). Only one-fifth (21%) said it was somewhat easy or very easy. Parents of children with autism spectrum disorder and those living in rural or suburban communities tended to report that finding help was more difficult.

Views of siblings. Almost three-quarters (74%) of siblings reported that it was very hard or somewhat hard to find the help their family member with a disability needed (see Figure D2). About one-quarter (26%) said it was somewhat easy or very easy.

Views of loved ones. Almost three-quarters (75%) of loved ones reported that it was very hard or somewhat hard to find the help their family member with a disability needed (see Figure D2). One-quarter (25%) said it was somewhat easy or very easy.

“A lot of government websites are difficult to understand and the information is hard to find. Also, it is so hard to get through on the phone.”

– Adult (in her 40s) with a mental health disorder

To gather more information about the most pressing needs of Tennesseans, we asked: **What is your biggest question or need right now related to disability?** In this optional open-ended question, the wording was tailored for each stakeholder group to match their relationship to individuals with disabilities. For example, the parent question referenced their child’s disability, while educators were asked about their students’ needs.

Responses were reviewed and grouped by topic. Across stakeholder groups, responses fell within 30 areas. These areas—presented by frequency—include: financial assistance, finding services, employment, transportation, respite or homecare, medical care, housing, transition, unknown future, mental health services, K-12 school, behavior, social skills or opportunities, adaptive equipment, coronavirus, community access, post-secondary education, therapy, communication, independence, basic needs, eligibility, conservatorship, where to start, understanding and acceptance, dental care, technology, early childhood education, culture, safety, and childcare or adult day programs (see Appendix D for definitions). Table D1 shows the top five question topics within each stakeholder group.

Table D1: Comparison across stakeholders: What is your biggest question or need right now related to disability?			
	Individuals	Families	Professionals
First Area	Employment	Financial assistance	Finding services
Second Area	Financial assistance	Finding services	Financial assistance
Third Area	Medical care	Respite or homecare	Transportation
Fourth Area	Transportation	Unknown future	Transition
Fifth Area	Finding services	K-12 school	Respite or homecare

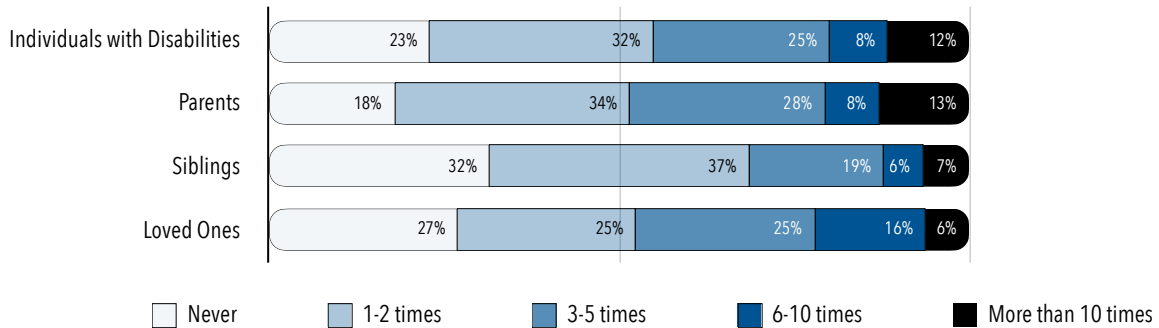
Additionally, we asked: **In the past year, how often did you or your family member with disabilities need information or help, but did not know where to get it?** This was asked of parents, loved ones, siblings, and individuals with disabilities (see Figure D3). We adjusted the wording based on each stakeholder group. Response options included *never*, *1-2 times*, *3-5 times*, *6-10 times*, or *more than 10 times*. As shown in Figure D4, professionals were provided with different response options: *never*, *rarely*, *sometimes*, and *often*.

“For me, I would say [finding resources and services] is almost a full-time job. It’s more than a hobby, I’ll tell you that.”

– Parent of a 24-year-old son

Figure D3

Comparison Across Stakeholders: In the past year, how often did you or your family member with disabilities need information or help, but did not know where to get it?



Views of individuals with disabilities. The percentage of individuals with disabilities who needed—but could not find—information or help three or more times in the last year was 45% (see Figure D3).

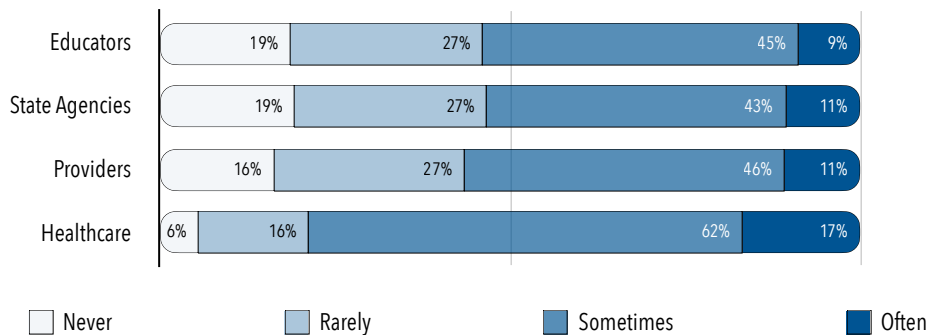
Views of parents. The percentage of parents who needed—but could not find—information or help three or more times in the last year was 49% (see Figure D3).

Views of siblings. The percentage of siblings who needed—but could not find—information or help three or more times in the last year was 32% (see Figure D3).

Views of loved ones. The percentage of loved ones who needed—but could not find—information or help three or more times in the last year was 47% (see Figure D3).

Figure D4

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



Views of educators. The percentage of educators who sometimes or often needed—but did not know where to find—information or help during the past year was 54% (see Figure D4). Educators who served

“We don’t know how to ask or who to ask.”

– Special educator with 5 years of experience

students with intellectual disability and autism spectrum disorder, who had less experience, and worked in suburban schools tended to report having a harder time finding needed information.

Views of state agency staff. The percentage of state agency staff who sometimes or often needed—but did not know where to find—information or help during the past year was 54% (see Figure D4). Staff with less experience tended to report having a harder time finding needed information.

Views of providers. The percentage of providers who sometimes or often needed—but did not know where to find—information or help during the past year was 57% (see Figure D4). Providers who served individuals with intellectual disability and autism spectrum disorder or who were White tended to report having a harder time finding needed information.

Views of healthcare workers. The percentage of healthcare workers who sometimes or often needed—but did not know where to find—information or help during the past year was 79% (see Figure D4). Those who were White tended to report having a harder time finding needed information.

Participants were asked a follow-up question about the types of information or help they had trouble locating. This optional question read: **What type of information or help were you looking for?** Responses were reviewed and grouped by topic. Across stakeholder groups, responses fell within 30 areas. These areas—presented by the frequency—include: employment, medical care, housing, mental health care, financial assistance, transportation, disability service system, K-12 school and learning, respite care, behavior supports or services, adult services, legal assistance, post-secondary options, therapies, basic needs, assistive technology, social opportunities, childcare, support groups, daily living support, dental care, coronavirus, disability evaluation, leisure and recreational activities, community events, home modifications, advocacy, dating and relationships, and summer camps or programs (see Appendix D for definitions). The top areas participants did not know where to find information or help are presented in Table D2.

Table D2: Comparison across stakeholders: Comparison across stakeholders: What type of information or help were you looking for?			
	Individuals	Families	Professionals
First Area	Employment	Employment	Housing
Second Area	Medical care	K-12 school and learning	Transportation
Third Area	Housing	Medical care	Financial assistance
Fourth Area	Transportation	Financial assistance	Mental health care
Fifth Area	Mental health care	Mental health care	Employment

“I feel like I can be more proactive for my parents if I’m aware of the services and things that are offered in the state.”

– Special educator with 32 years of experience

Participants were asked to share more about their experiences finding disability information. This optional question read: **What (if anything) makes it hard to find the information you need?** Responses were reviewed and grouped by experience. Across stakeholder groups, responses fell within 19 areas. These areas—presented by frequency—include: difficulty finding information, unsure where to start, lack of resources, connecting with service providers, lack of organization, no supports for my location, misinformation/credibility, financial issue, lack of specificity, time commitment, access to technology, personal problem, rare disability, accessibility of resources, trouble understanding information, ineligible, feel overwhelmed, coronavirus, and need for social interaction (see Appendix D for definitions). Table D3 shows the top five responses within each stakeholder group.

Table D3: Comparison across stakeholders: What (if anything) makes it hard to find the information you need?			
	Individuals	Families	Professionals
First Area	Difficulty finding information	Unsure where to start	No supports for my location
Second Area	Connecting with service providers	Difficulty finding info	Lack of organization
Third Area	Unsure where to start	Lack of resources	Misinformation/credibility
Fourth Area	Lack of resources	Connecting with service providers	Difficulty finding information
Fifth Area	Access to technology	No supports for my location	Connecting with service providers

↘ Key Points and Implications

- » There were very mixed views regarding how easy it is to find needed disability information, within and across stakeholder groups.
- » Among individuals and family members, however, a substantial majority of people considered this task to be quite hard. Organizations and professionals must identify ways to ease this challenge so that people can access the much-needed information and assistance.
- » Individuals and families identified a broad spectrum of topics on which they had pressing questions (e.g., financial assistance, transportation, respite, finding services). Organizations and professionals should identify the extent to which they have information or guidance addressing each of these key topics, developing new resources as needed.
- » The *Tennessee Disability Pathfinder* website and helpline should be vigorously promoted throughout all corners of the state.
- » Professionals also shared their difficulties knowing where to find needed information. Because many individuals and families first turn to professionals for information and help, state agencies should ensure their staff and partners are familiar with *Pathfinder* and other helpful information sources in our state (e.g., disability organizations, technical assistance projects).

WE CONCLUDE THIS SECTION WITH A
SAMPLING OF QUOTES RELATING TO THE FINDING
INFORMATION OR AVAILABILITY OF SERVICES:

“The phrase that comes up for me is *feast* or *famine*. Because, depending on what the disability is, sometimes you’re inundated with information. But then, if it’s something not as common or a challenge, there’s not a lot of information out there about it and it’s hard to find. So, it’s either one or the other.”

– Disability organization staff with 3 years of experience

“I would say finding the time to keep information current, you know, just requires time that I don’t always have.”

– Special educator with 30 years of experience

“It’s really a frustrating thing for our families. And it can be really hard as a teacher to get blamed for not having that information.”

– Special educator with 5 years of experience

“I know there’s some good things that are going on, but it’s unclear as to what those are. And it’s very hard to transfer that information into parents’ knowledge banks and teachers for that matter.”

– Disability organization staff with 28 years of experience

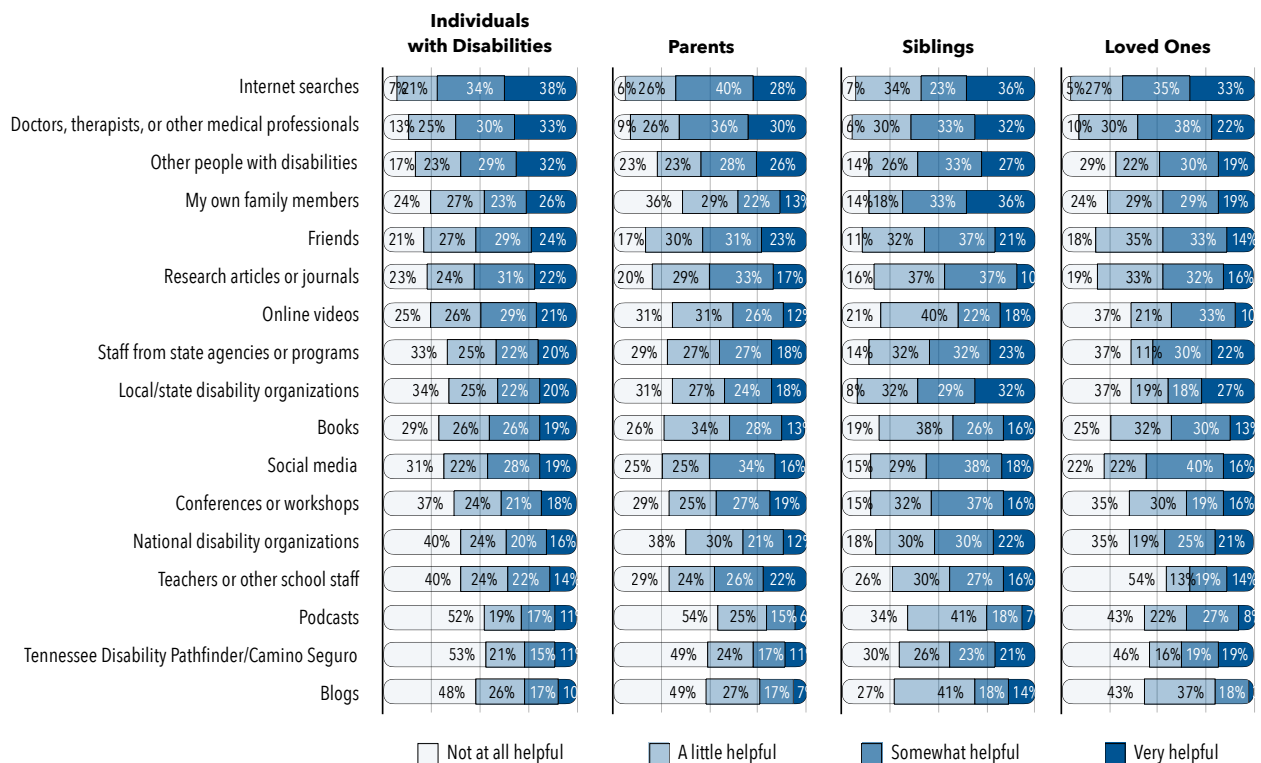
HOW DO TENNESSEANS FIND INFORMATION AND SERVICES?

We wanted to learn more about where individuals with disabilities, their families, and professionals turn for information. Their views on which sources of information are most helpful can help inform how resources and guidance are shared across the state.

The main survey question on this topic read: **What sources of information or resources about disability do you find helpful?** We provided a list of 17 avenues through which people might seek out information related to disability (see Figures E1 and E2). They could respond with one of four choices: *not at all helpful*, *a little helpful*, *somewhat helpful*, or *very helpful*. The wording of the third answer choice (i.e., “other families or people with disabilities”) differed by stakeholder group. Specifically, individuals with disabilities were given the option of “other people with disabilities”; parents, siblings, and loved ones were given the option of “other families with members with disabilities.”

Figure E1

Comparison Across Stakeholders: What sources of information or resources about disability do you find helpful?



“Honestly, I am not aware of many resources. Nor do I know how to search for them.”

– Adult (in her 30s) with multiple disabilities

Views of individual with disabilities. The three sources of information most often considered somewhat or very helpful by individuals with disabilities were (see Figure E1):

- Internet searches (72%)
- Doctors, therapists, or other medical professionals (63%)
- Other people with disabilities (60%)

Views of parents. The three sources of information most often considered somewhat or very helpful by parents were (see Figure E1):

- Internet searches (68%)
- Doctors, therapists, or other medical professionals (66%)
- Other families with members with disabilities (54%)

Views of siblings. The three sources of information most often considered somewhat or very helpful by siblings were (see Figure E1):

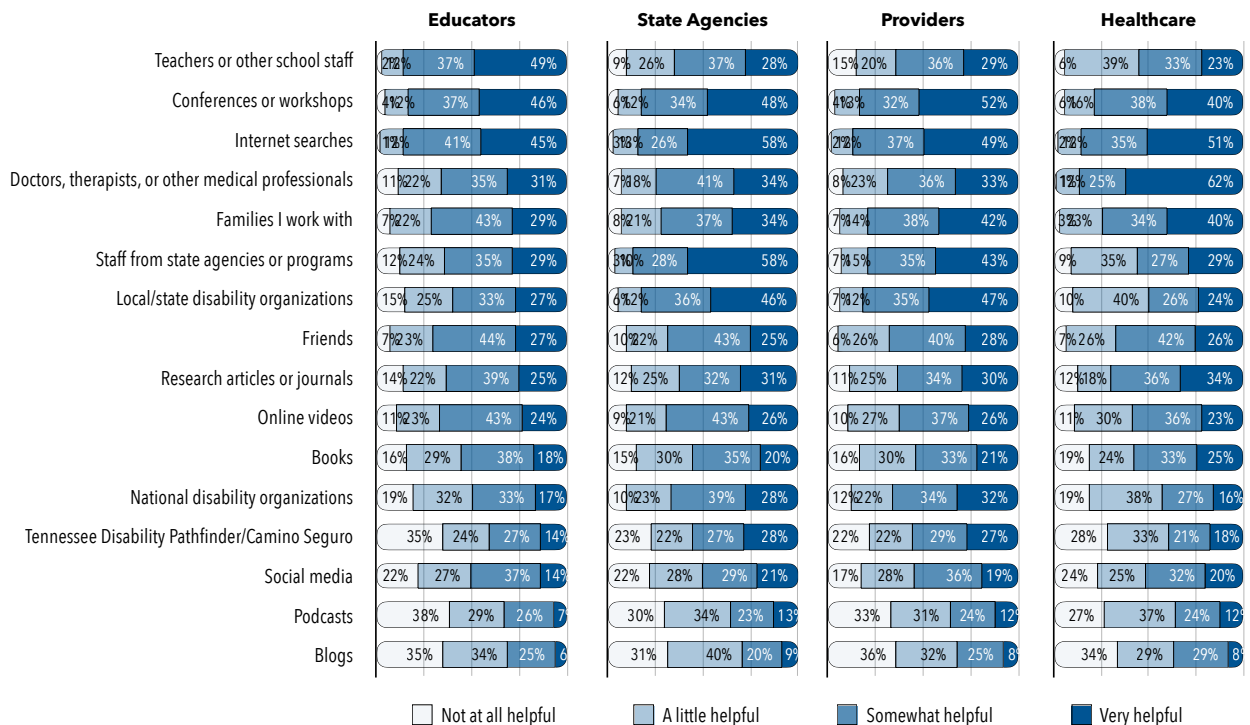
- My own family members (69%)
- Doctors, therapists, or other medical professionals (66%)
- Local/state disability organizations (61%)

Views of loved ones. The three sources of information most often considered somewhat or very helpful by loved ones were (see Figure E1):

- Internet searches (68%)
- Doctors, therapists, or other medical professionals (60%)
- Social media (56%)

Figure E2

Comparison Across Stakeholders: What sources of information or resources about disability do you find helpful?



Views of educators. The three sources of information most often considered somewhat or very helpful by educators were (see Figure E2):

- Internet searches (86%)
- Fellow teachers or other school staff (86%)
- Conferences or workshops (84%)

Educators were asked an additional question relating to a source of information and its helpfulness. This source read “school-provided professional development.” Over a half of educators viewed this as somewhat or very helpful (60%); 13% of educators found this as not at all helpful.

Views of state agency staff. The sources of information most often considered somewhat or very helpful by state agency staff were (see Figure E2):

- Fellow staff from state agencies or programs (86%)
- Internet searches (84%)
- Conferences or workshops (83%)

Views of providers. The three sources of information most often considered somewhat or very helpful by providers were (see Figure E2):

- Internet searches (86%)
- Conferences or workshops (84%)
- Local/state disability organizations (82%)

Views of healthcare workers. The three sources of information most often considered somewhat or very helpful by healthcare workers were (see Figure E2):

- Fellow doctors, therapists, or other medical professionals (87%)
- Internet searches (85%)
- Conferences or workshops (79%)

Other sources. We also included an open-ended question in which everyone could add other sources of information that were not listed. Below is a sampling of those responses:

- Caregivers or advocates
- Community events
- Faith community (e.g., special needs ministry programs)
- Grant projects/programs (e.g., ASSIST: Advocating for Support to Improve Service Transition, Vanderbilt TRIAD: Treatment & Research Institute for Autism Spectrum Disorders)
- Newspaper
- Print materials (e.g., flyers, brochures)
- Radio programs
- Summer camps
- Support groups (e.g., peers, parents, online forums)
- Television shows
- Veterans Affairs

“There may be programs available and the information may be out there, but it’s a full-time job. When you are a single parent with two other children. Who has the bandwidth to chase this down when the most important thing is to provide a stable home and food?”

– Parent of a 24-year-old son

The second survey question on this topic read: **Which are three sources of information you use most?** Participants were asked to select their top three from the list in the previous question. Below is a summary of the choices selected most often by individuals, parents, siblings, and loved ones (see Table E1). The same question was asked of educators, state agency staff, providers, and healthcare workers (see Table E2).

Table E1: Comparison across stakeholders: Which are three sources of information you use most?				
	Individuals	Parents	Siblings	Loved ones
First Choice	Internet searches	Internet searches	Internet searches	Internet searches
Second Choice	Social media	Social media	Social media; Other families; Doctors, therapists, and other medical professionals	Doctors, therapists, and other medical professionals
Third Choice	Doctors, therapists, and other medical professionals	Doctors, therapists, and other medical professionals	Local/state disability organizations	Research articles or journals

Table E2: Comparison across stakeholders: Which are three sources of information you use most?				
	Educators	State Agencies	Providers	Healthcare
First Choice	Internet searches	Internet searches	Internet searches	Internet searches
Second Choice	Teachers or other school staff	Staff from state agencies or programs	Local/state disability organizations	Doctors, therapists, and other medical professionals
Third Choice	Conferences or workshops	Conferences or workshops	Conferences or workshops	Research articles or journals; Conferences or workshops

Participants were asked to identify which websites or organizations they use most frequently to find disability information. This optional question read: **List any specific websites or organizations you visit frequently for disability information.** The responses were categorized by type of source where the participant found disability information. Across stakeholder groups, websites/organizations fell within twelve categories. These categories—presented by frequency—include: national disability specific sites, state agencies or programs, Tennessee disability non-profits, social media, national disability non-profits, Tennessee disability specific sites, general search engines, federal programs, podcasts/YouTube, other websites, state specific sites (see Appendix E for definitions). Table E3 shows the top five websites or organizations used by each stakeholder group.

“Families are already facing a deluge of information and school-related communication. It has to be targeted and directly/immediately relevant to their child.”

– School administrator with 4 years of experience

Table E3: Comparison across stakeholders: List any specific websites or organizations you visit frequently for disability information.

	Individuals	Families	Professionals
First Area	National disability specific site	National disability specific sites	State agency or program
Second Area	National disability non-profit	Tennessee disability non-profit	National disability non-profit
Third Area	Social media	State agency or program	Tennessee disability non-profit
Fourth Area	State agency or program	Social media	Social media
Fifth Area	Tennessee disability non-profit	Tennessee disability specific site	Tennessee disability specific sites

↘ Key Points and Implications

- » Numerous avenues now exist for accessing disability-related information. It is clear that Tennesseans turn to a wide array of sources in their own pursuit of information.
- » Internet searches were the top choice for information across all eight stakeholder groups. State agencies and organizations should work to optimize websites with the most relevant keywords and tags so that information is more easily found through searches.
- » Social media was also prominent among individuals with disabilities and their families. State agencies and programs should consider how to best to utilize these evolving forums as an additional way of equipping people with resources and connections they need.
- » Doctors, therapists, and other medical professionals are highly trusted by individuals with disabilities and their families and a key source of guidance. Creative partnerships with healthcare offices could provide another way of connecting individuals and families to information unrelated to their health.
- » Conferences and workshops continue to be a primary avenue through which professionals learn needed information. Expanding access to such professional development events and ensuring they are of high quality is an important investment.
- » Many professionals rightfully turn to one another for advice and strategies. Establishing communities of practice, peer networks, and other relational forums could further strengthen the connections professionals have to their colleagues.
- » Ask your staff about the various places they turn when they need information. Ensure they are familiar with *Tennessee Disability Pathfinder*, relevant state and national disability organizations, and other reliable resources. Likewise, ask them about topics that regularly come up for which they need more guidance.

WE CONCLUDE THIS SECTION WITH A SAMPLING OF QUOTES
RELATING TO THE IMPORTANCE OF VARIOUS EXPERIENCES:

“I research my condition and build my own solutions where I can.”

– Adult (in his 40s) with various disabilities

“We share information in IEP meetings and besides that, it is usually like putting individual fires out. When one family has a need, I research it and send it to them. When another family has a different need, I do the same thing. I would like to be proactive, but I don’t know how.”

– Special educator with 1.5 years of experience

“As a parent of an adult child with disabilities, we felt overwhelmed and powerless. I have worked with individuals and families as an advocate for people with disabilities for years and yet I could not figure out how to get my son access to the support or tools he needed to maintain his benefits necessary to live and be productive.”

– Parent of a 33-year-old son

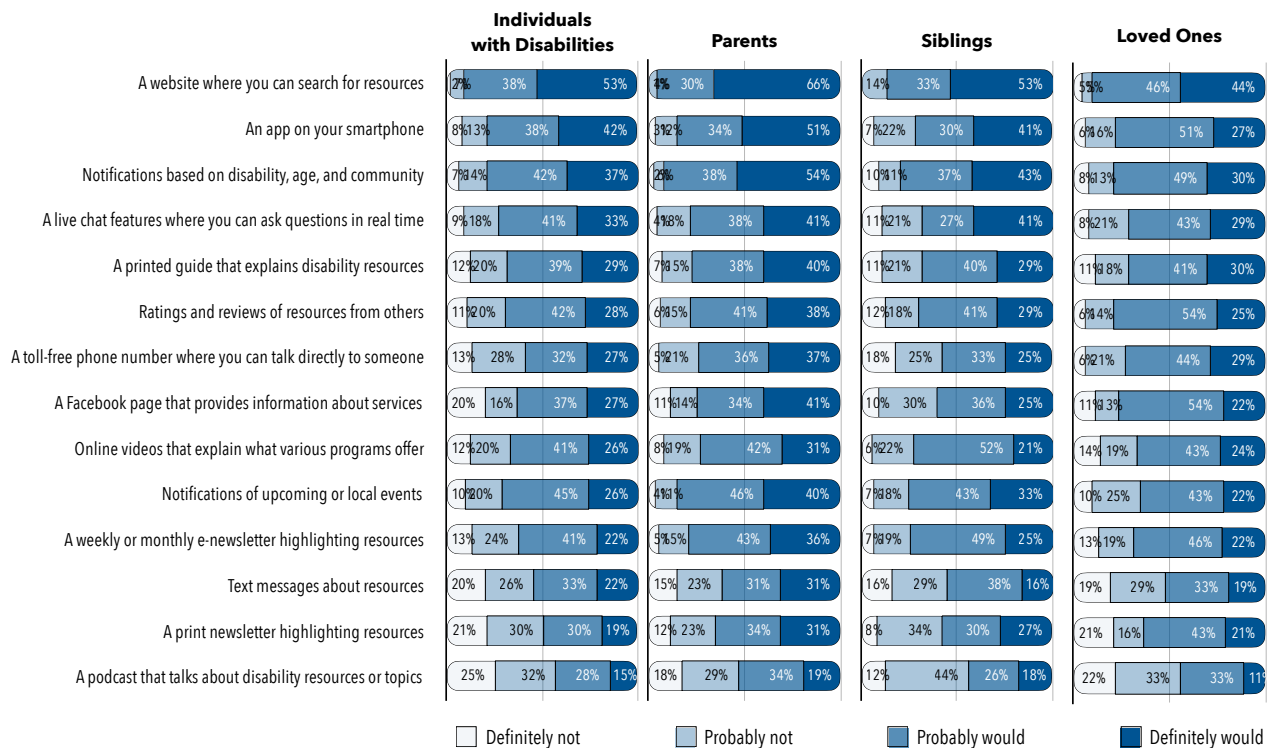
WHAT RESOURCES COULD BE HELPFUL FOR TENNESSEANS?

We wanted to learn about the suggestions Tennesseans have for improving how disability information is shared and help is found. This question was presented to all eight stakeholder groups. Their feedback suggests an array of resources that could be especially helpful for disability organizations, state agencies, and other groups to develop or expand.

The main survey question on this topic read: **How likely would you be to use each of the following if it was available?** A list of various resources that could be used to find information more easily was presented to individuals with disabilities, parents, siblings, and loved ones (see Figure F1). The same resources were also presented to educators, state agency staff, providers, and healthcare workers (see Figure F2). They could indicate their anticipated use with the following response options: *definitely not*, *probably not*, *probably would*, or *definitely would*. The wording of some resource options varied slightly depending on the stakeholder.

Figure F1

Comparison Across Stakeholders: How likely would you be to use each of the following if it was available?



Views of individuals with disabilities. The three resources which the highest percentage of individuals with disabilities said they would probably or definitely use were (see Figure F1):

- A website where you can search for resources (91%)
- An app on your smartphone (79%)
- Notifications based on disability, age, and community (79%)

Views of parents. The three resources which the highest percentage of parents said they would probably or definitely use were (see Figure F1):

- A website where you can search for resources (96%)
- Notifications based on disability, age, and community (92%)
- Notifications of upcoming or local events (86%)

Views of siblings. The three resources which the highest percentage of siblings said they would probably or definitely use were (see Figure F1):

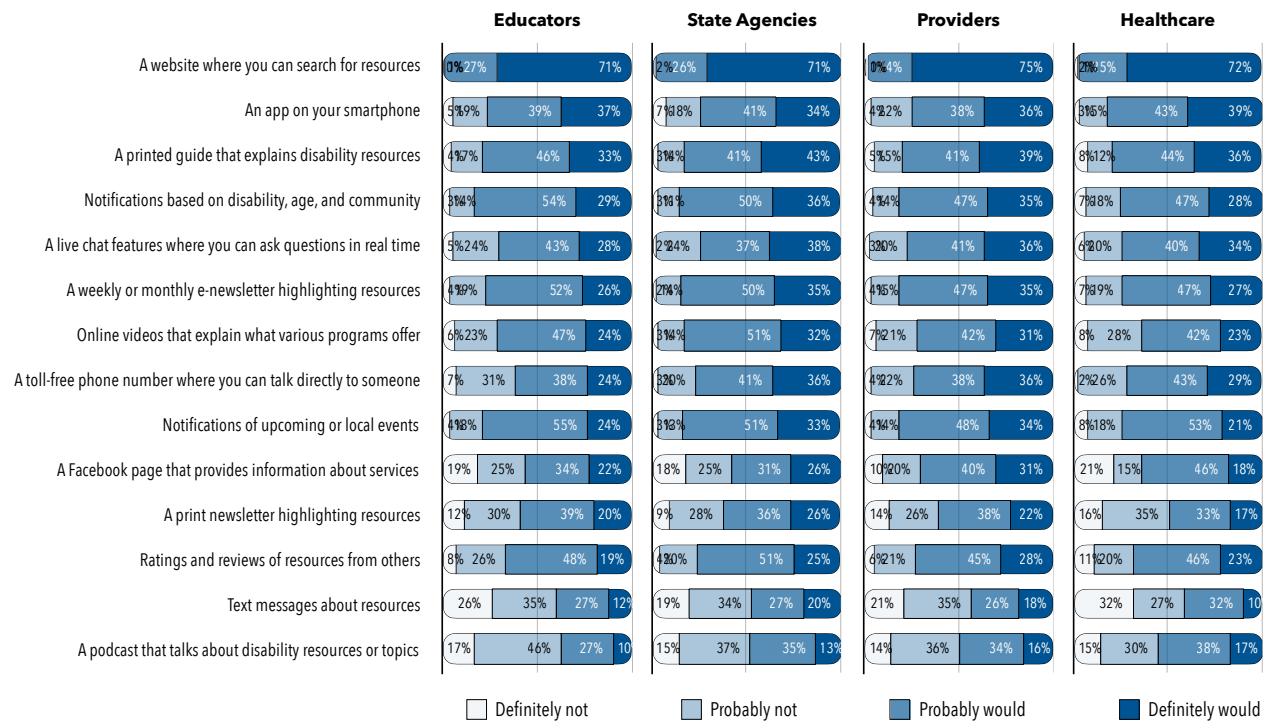
- A website where you can search for resources (86%)
- Notifications based on disability, age, and community (80%)
- Notifications of upcoming or local events (75%)

Views of loved ones. The three resources which the highest percentage of loved ones said they would probably or definitely use were (see Figure F1):

- A website where you can search for resources (90%)
- Ratings and reviews of resources of others (79%)
- Notifications based on disability, age, and community (79%)

Figure F2

Comparison Across Stakeholders: How likely would you be to use each of the following if it was available?



Views of educators. The three resources that the highest percentage of surveyed educators probably or definitely would use were (see Figure F2):

- A website where you can search for resources (99%)
- Notifications based on disability, age, and community (83%)
- Notifications of upcoming or local events (79%)
- A printed guide that explains disability resources (79%)

Views of state agency staff. The three resources that the highest percentage of surveyed state agency staff probably or definitely would use were (see Figure F2):

- A website where you can search for resources (98%)
- Notifications based on disability, age, and community (86%)
- A weekly or monthly e-newsletter highlighting resources (85%)

Views of providers. The three resources that the highest percentage of surveyed providers probably or definitely would use were (see Figure F2):

- A website where you can search for resources (98%)
- Notifications of upcoming or local events (82%)
- A weekly or monthly e-newsletter highlighting resources (82%)

View of healthcare. The three resources that the highest percentage of surveyed healthcare workers probably or definitely would use were (see Figure F2):

- A website where you can search for resources (97%)
- An app on your smartphone (82%)
- A printed guide that explains disability resources (80%)

Participants were asked to share their recommendations for making disability information simpler to locate. This optional question read: **Share any other ideas you have for making disability information easier to find.** Responses were reviewed and grouped by suggestion type. Suggestions—presented by frequency—include: streamline information, personalize resources, educate professionals, connect families, talk with real person, offer non-internet resources, involve healthcare professionals, advertise *Pathfinder*, improve website navigation, connect self-advocates, update resources, use social media, create an app, provide training for families, and use direct email (see Appendix F for definitions). Table F1 shows the top five ideas for how disability information can be made easier to find within each stakeholder group.

Table F1: Comparison across stakeholder groups: Share any other ideas you have for making disability information easier to find.			
	Individuals	Families	Professionals
First Area	Streamline information	Personalize resources	Educate professionals
Second Area	Personalize resources	Connect families	Streamline information
Third Area	Talk with real person	Streamline information	Personalize resources
Fourth Area	Connect self-advocates	Educate professionals	Offer non-internet resources
Fifth Area	Use social media	Involve healthcare professionals	Advertise <i>Pathfinder</i>

↳ Key Points and Implications

- » Nearly all of the ideas suggested in this section were endorsed by the majority of individuals with disabilities, family members, and professionals. Thus, if implemented, each idea is likely to be drawn upon by large numbers of Tennesseans.
- » Some of the resource ideas listed in this section already exist, such as a website where one can search for resources and a toll-free helpline (both provided by *Tennessee Disability Pathfinder*). These resources should be more heavily publicized in an ongoing way.
- » Many of the ideas could be adopted by individual agencies and organizations in the state. This might include introducing live chat features into websites, developing printed resource guides that could be distributed to stakeholders, investing in a more substantive social media presence, or creating compelling videos describing services.
- » The ubiquity of smart phones affirms the value of pursuing development of one or more practical apps. This could be done in conjunction with *Tennessee Disability Pathfinder* as a one-stop app, or approached in other ways.
- » Similar questions could be posed to your own constituents periodically to see which (or which other) resources they would most like to see developed.

PARTICIPANT DEMOGRAPHICS

Table A1. Individuals with Disabilities Demographics (N = 726)

Variable	%	Variable	%
Age		Do You Have a Paid Job?	39.8
Under 20	7.3	Have You Served in the military?	5.2
20-29	27.8	Community Type	
30-39	16.0	Rural	36.4
40-49	20.0	Suburban	36.8
50-59	14.9	Urban	22.5
60-69	11.6	Prefer not to answer	4.4
70 or older	2.2	Disability Type ^a	
Prefer not to answer	0.3	Autism spectrum disorder	9.8
Sex		Deaf-blindness	5.6
Female	65.6	Deafness	10.2
Male	32.8	Developmental delay	4.1
Intersex	0.1	Hearing impairment	11.4
Prefer not to answer	1.5	Learning disability	15.0
Sexual Orientation		Intellectual disability	4.1
Heterosexual or straight	82.4	Mental illness, mental health disorder, or EBD	33.3
Gay or lesbian	3.4	Other health impairment or ADD/ADHD	16.7
Bisexual/pansexual	5.5	Physical disability	40.2
Questioning/unsure	1.7	Speech/language impairment	3.9
Other	1.8	Traumatic brain injury	7.2
Prefer not to answer	0.3	Visual impairment	12.4
Race/Ethnicity		Substance abuse disorder	2.6
American Indian and Alaska Native	3.3	Other	13.1
Asian	2.5	Self-Described Support Needs	
Black or African American	16.3	No support	15.8
Hispanic/Latino	3.6	A little support	27.1
Native Hawaiian & Other Pacific Islander	0.1	Some support	38.2
White	73.8	A lot of support	14.0
Other	1.2	Total support	2.9
Prefer not to answer	3.3	Prefer not to answer	1.9
Marital Status		Self-Described Overall Physical Health	
Single	51.8	Poor	9.8
Married/living with partner	28.9	Fair	36.1
Separated/divorced	14.2	Good	34.4
Widowed	2.8	Very good	14.9
Prefer not to answer	2.3	Excellent	4.4
Highest Level of Education		Prefer not to answer	0.4
High school or less	4.7	Census Questions	
High school diploma or GED	15.4	Deaf or serious difficulty hearing	20.0
Some college	29.9	Blind or serious difficulty seeing when wearing glasses	13.8
Certification program	6.3	Serious difficulty walking or climbing	38.6
Associates (two-year degree)	8.8	Difficulty dressing or bathing	21.6
Bachelors (four-year degree)	19.4	Difficulty doing errands	49.7
Masters' degree	13.1		
Doctoral degree	1.5		
Prefer not to answer	0.8		

^a More than one option could be selected.

Table A2. Parent Demographics (N = 1081)

Variable	%
Age	
Under 20	0.0
20-29	3.3
30-39	21.1
40-49	34.0
50-59	24.1
60-69	13.8
70 or older	3.1
Prefer not to answer	0.6
Sex	
Female	87.7
Male	12.1
Intersex	0.0
Prefer not to answer	0.2
Race/Ethnicity	
American Indian and Alaska Native	2.3
Asian	0.9
Black or African American	10.2
Hispanic/Latino	6.1
Native Hawaiian & Other Pacific Islander	0.3
White	78.8
Other	0.4
Prefer not to answer	3.7
Marital Status	
Single	7.7
Married/living with partner	75.6
Separated/divorced	11.8
Widowed	3.5
Prefer not to answer	1.4
Highest Level of Education	
High school or less	3.1
High school diploma or GED	10.0
Some college	19.3
Certification program	5.6
Associates (two-year degree)	9.0
Bachelors (four-year degree)	28.0
Master's degree	19.8
Doctoral degree	4.3
Prefer not to answer	0.9
Community Type	
Rural	35.9
Suburban	44.5
Urban	15.6
Prefer not to answer	4.0

Demographics of their children									
	Child 1 (N=1081)	Child 2 (N=149)	Child 3 (N=39)	Child 4 (N=8)		Child 1 (N=1081)	Child 2 (N=149)	Child 3 (N=39)	Child 4 (N=8)
Age					Does the Child Live in the Same City?				
Under 20	66.0	75.8	69.2	37.5	Yes	72.9	38.5	25.0	50.0
20-29	22.1	20.1	28.2	37.5	No	27.1	61.5	75.0	50.0
30-39	8.1	2.0	2.6	25.0	Perceived Support Needs				
40-49	3.0	1.3	0.0	0.0	No support	4.1	12.1	20.5	25.0
50-59	0.6	0.7	0.0	0.0	A little support	18.7	24.8	15.4	25.0
60-69	0.2	0.0	0.0	0.0	Some support	31.5	31.5	25.6	12.5
70 or older	0.0	0.0	0.0	0.0	A lot of support	31.6	22.1	23.1	12.5
Sex					Total support	14.2	9.4	15.4	25.0
Female	37.1	29.5	41.0	50.0	Overall Physical Health				
Male	62.8	69.1	59.0	50.0	Poor	3.6	1.3	2.6	0.0
Intersex	0.1	1.3	0.0	0.0	Fair	17.6	12.1	12.8	12.5
Disability Type^a					Good	38.1	37.6	35.9	50.0
Autism spectrum disorder	46.4	6.3	1.6	0.4	Very good	30.4	33.6	33.3	12.5
Deaf-blindness	3.8	0.7	0.1	0.0	Excellent	10.3	15.4	15.4	25.0
Deafness	6.8	0.6	0.0	0.0	Frequency of Challenging Behavior				
Developmental delay	45.1	4.2	1.7	0.3	Never	41.3	36.2	33.3	37.5
Hearing impairment	9.8	1.0	0.1	0.0	Yearly	13.0	12.8	10.5	12.5
Learning disability	38.2	5.6	1.9	0.3	Monthly	15.3	14.8	20.5	12.5
Intellectual disability	45.3	3.9	1.7	0.4	Weekly	15.8	14.8	20.5	25.0
Mental illness, mental health disorder, or EBD	18.9	4.0	1.8	0.5	Daily	14.6	21.5	15.4	12.5
Other health impairment or ADD/ADHD	23.7	5.7	1.3	0.2	Communication Mode				
Physical disability	22.8	2.3	0.8	0.2	Talking	70.8	85.3	79.5	75.0
Speech/language impairment	39.1	3.9	1.3	0.0	Using pictures or communication device	3.4	2.7	2.6	0.0
Traumatic brain injury	6.8	0.5	0.1	0.0	Sign language or other signs	5.6	0.0	2.6	12.5
Visual impairment	11.8	1.4	0.5	0.0	Gestures, facial expressions, sounds, or body movements	15.4	10.1	10.3	12.5
Substance abuse disorder	0.8	0.4	0.0	0.0	My child does not intentionally communicate with others	4.8	2.0	5.1	0.0
Other	12.1	2.3	0.7	0.1	Census Questions				
Where Does the Child Live?					Deaf or serious difficulty hearing	13.8	10.7	2.6	0.0
In the same home or apartment as me	91.1	91.3	89.7	50.0	Blind or serious difficulty seeing when wearing glasses	12.9	10.1	12.8	0.0
In their own place	5.5	6.0	5.1	12.5	Serious difficulty walking or climbing	23.8	16.1	23.1	12.5
In a group home	1.3	0.7	0.0	12.5	Difficulty dressing or bathing	43.4	28.2	35.9	12.5
In a nursing facility	0.6	0.0	0.0	12.5	Difficulty doing errands	72.1	57.7	64.1	75.0
Somewhere else	1.5	2.0	5.1	12.5	Has a Paid Job	20.4	23.3	25.0	42.9

^a More than one option could be selected.

Table A3. Sibling Demographics (N = 73)

Variable	%
Age	
Under 20	8.2
20-29	39.7
30-39	24.7
40-49	8.2
50-59	8.2
60-69	6.8
70 or older	4.1
Prefer not to answer	0.0
Sex	
Female	67.1
Male	32.9
Prefer not to answer	0.0
Race/Ethnicity	
American Indian and Alaska Native	8.2
Asian	6.8
Black or African American	16.4
Hispanic/Latino	6.8
Native Hawaiian & Other Pacific Islander	1.4
White	58.9
Other	1.4
Prefer not to answer	1.4
Marital Status	
Single	39.7
Married/living with partner	56.2
Separated/divorced	2.7
Widowed	0.0
Prefer not to answer	1.4
Highest Level of Education	
High school or less	5.5
High school diploma or GED	6.8
Some college	39.7
Certificate program	5.5
Associates (two-year degree)	2.7
Bachelors (four-year degree)	20.5
Masters degree	16.4
Doctoral degree	2.7
Prefer not to answer	0.0
Community Type	
Rural	39.7
Suburban	32.9
Urban	26.0
Prefer not to answer	1.4

Demographics of their siblings

	Sibling 1 (N=73)	Sibling 2 (N=5)	Sibling 3 (N=2)	Sibling 4 (N=1)
Age				
Under 20	41.1	40.0	100	100
20-29	17.8	20.0	0.0	0.0
30-39	16.4	20.0	0.0	0.0
40-49	5.5	0.0	0.0	0.0
50-59	8.2	2.0	0.0	0.0
60-69	9.6	0.0	0.0	0.0
70 or older	1.4	0.0	0.0	0.0
Sex				
Female	39.7	20.0	0.0	0.0
Male	60.3	80.0	100	100
Intersex	0.0	0.0	0.0	0.0
Disability Type^a				
Autism spectrum disorder	21.9	1.4	0.0	0.0
Deaf-blindness	13.7	0.0	0.0	0.0
Deafness	15.1	1.4	1.4	0.0
Developmental delay	20.5	2.7	1.4	1.4
Hearing impairment	15.1	0.0	0.0	0.0
Learning disability	27.4	2.7	1.4	0.0
Intellectual disability	35.6	2.7	1.4	0.0
Mental illness, mental health disorder, or EBD	8.2	1.4	0.0	0.0
Other Health Impairment or ADD/ADHD	5.5	0.0	0.0	0.0
Physical disability	37.0	4.1	1.4	0.0
Speech/language impairment	23.3	1.4	1.4	0.0
Traumatic brain injury	6.8	0.0	0.0	0.0
Visual impairment	17.8	1.4	0.0	0.0
Substance abuse disorder	0.0	0.0	0.0	0.0
Other	4.1	0.0	0.0	0.0
Do They Live with You?				
Yes	53.4	40.0	50.0	0.0
No	46.6	60.0	50.0	100
Do They Live in the Same City?				
Yes	57.1	33.3	0.0	0.0
No	46.6	66.7	100	100

^a More than one option could be selected.

	Sibling 1 (N=73)	Sibling 2 (N=5)	Sibling 3 (N=2)	Sibling 4 (N=1)
Perceived Support Needs				
No support	2.7	0.0	0.0	0.0
A little support	15.1	40.0	0.0	0.0
Some support	35.6	40.0	50.0	0.0
A lot of support	35.6	20.0	0	0.0
Total support	11.0	0.0	50.0	100.0
Overall Physical Health				
Poor	15.1	0.0	0.0	0.0
Fair	31.5	20.0	0.0	100.0
Good	39.7	40.0	50.0	0.0
Very good	11.0	40.0	50.0	0.0
Excellent	2.7	0.0	0.0	0.0
Frequency of Challenging Behavior				
Never	39.7	20.0	50.0	100
Yearly	26.0	0	50.0	0.0
Monthly	12.3	40	0.0	0.0
Weekly	13.7	20	0.0	0.0
Daily	8.2	20	0.0	0.0
Communication Mode				
Talking	56.2	40.0	0.0	0.0
Using pictures or communication device	4.1	0.0	50.0	100
Sign language or other signs	12.3	20.0	0.0	0.0
Gestures, facial expressions, sounds, or body movements	26.0	40.0	0.0	0.0
My sibling does not intentionally communicate with others	1.4	0.0	50.0	0.0
Census Questions				
Deaf or serious difficulty hearing	35.6	40.0	50.0	0.0
Blind or serious difficulty seeing when wearing glasses	24.7	20.0	50.0	0.0
Serious difficulty walking or climbing	43.8	60.0	50.0	0.0
Difficulty dressing or bathing	42.5	40.0	50.0	0.0
Difficulty doing errands	76.7	60.0	50.0	0.0
Has a Paid Job	26.9	0.0	N/A	N/A

Table A4. Loved One Demographics (N = 63)

Variable	%
Age	
Under 20	4.8
20-29	6.3
30-39	27.0
40-49	20.6
50-59	27.0
60-69	12.7
70 or older	1.6
Sex	
Female	84.1
Male	15.9
Intersex	0.0
Prefer not to answer	0.0
Race/Ethnicity	
American Indian and Alaska Native	12.7
Asian	3.2
Black or African American	14.3
Hispanic/Latino	1.6
Native Hawaiian & Other Pacific Islander	1.6
White	68.3
Other	0.0
Prefer not to answer	0.0
Marital Status	
Single	7.9
Married/living with partner	79.4
Separated/divorced	11.1
Widowed	1.6
Prefer not to answer	0.0
Highest Level of Education	
High school or less	1.6
High school diploma or GED	7.9
Some college	49.2
Certification program	9.5
Associates (two-year degree)	4.8
Bachelors (four-year degree)	17.5
Master's degree	7.9
Doctoral degree	1.6
Prefer not to answer	0.0
Community Type	
Rural	39.7
Suburban	38.1
Urban	19.0
Prefer not to answer	3.2

Demographics of their loved one

Variable	%
Age	
Under 20	9.5
20-29	9.5
30-39	12.7
40-49	12.7
50-59	22.2
60-69	12.7
70 or older	20.6
Sex	
Female	30.2
Male	69.8
Intersex	0.0
Disability Type^a	
Autism spectrum disorder	4.8
Deaf-blindness	19.0
Deafness	19.0
Developmental delay	1.6
Hearing impairment	15.9
Learning disability	7.9
Intellectual disability	3.2
Mental illness, mental health disorder, or EBD	19.0
Other health impairment or ADD/ADHD	4.8
Physical disability	52.4
Speech/language impairment	7.9
Traumatic brain injury	11.1
Visual impairment	9.5
Substance abuse disorder	1.6
Other	12.7
Perceived Support Needs	
No support	6.3
A little support	15.9
Some support	33.3
A lot of support	28.6
Total support	15.9

^aMore than one option could be selected.

Variable	%
Loved ones overall physical health	
Poor	11.1
Fair	46.0
Good	31.7
Very good	11.1
Excellent	0.0
Do They Live with You?	
Yes	88.9
No	11.1
Do They Live in the Same City?	
Yes	50.0
No	50.0
Has a Paid Job	
Yes	17.5
No	81.0
Unsure	1.6
Census Questions	
Deaf or serious difficulty hearing	20.0
Blind or serious difficulty seeing when wearing glasses	13.8
Serious difficulty walking or climbing	38.6
Difficulty dressing or bathing	21.6
Difficulty doing errands	49.7
Communication Mode	
Talking	65.1
Using pictures or communication device	0.0
Sign language or other signs	14.3
Gestures, facial expressions, sounds, or body movements	19.0
My loved one does not intentionally communicate with others	1.6

Table A5. Educator Demographics (N = 504)

Variable	%
Age	
20-29	10.3
30-39	20.4
40-49	24.0
50-59	28.2
60-69	15.5
70 or older	0.2
Prefer not to answer	1.4
Sex	
Female	89.3
Male	9.1
Prefer not to answer	1.6
Race/Ethnicity	
American Indian and Alaska Native	1.2
Asian	1.2
Black or African American	8.7
Hispanic/Latino	3.4
Native Hawaiian & Other Pacific Islander	0.6
White	83.9
Other	0.2
Prefer not to answer	4.0
Professional Role	
Special educator	57.7
General educator	3.4
Paraprofessional	5.0
Related service provider	9.1
Administrator	10.7
Other	14.1
School Level	
Early childhood, early intervention, or birth to three	3.6
Pre-K	20.4
Elementary school	39.9
Middle school	41.3
High school	52.0
Postsecondary/college	8.9

Variable	%
School Setting	
Public schools	90.9
Charter schools	3.8
Private schools	5.4
Special Education Categories Served^a	
Autism spectrum disorder	87.5
Deaf-blindness	13.7
Deafness	15.7
Developmental delay	60.7
Hearing impairment	37.3
Learning disability	76.2
Intellectual disability	72.4
Mental illness, mental health disorder, or EBD	56.5
Multiple disabilities	62.3
Other health impairment or ADD/ADHD	81.0
Physical disability	39.1
Speech/language impairment	76.2
Traumatic brain injury	30.6
Visual impairment	41.5
Students on 504 Plans	25.6
Other	3.0
Proportion of Caseload with Severe Disabilities	
None	16.6
1-24%	38.3
25-49%	13.4
50-74%	5.9
75-99%	7.4
All	18.4
Type of Community You Work In	
Rural	44.6
Suburban	33.3
Urban	22.0

^aMore than one option could be selected.

Table A6. Disability Provider Demographics (N = 294)

Variable	%
Age	
Under 20	0.0
20-29	8.5
30-39	19.4
40-49	26.2
50-59	24.5
60-69	17.0
70 or older	3.7
Prefer not to answer	0.7
Sex	
Female	84.0
Male	15.6
Intersex	0.0
Prefer not to answer	0.3
Race/Ethnicity	
American Indian and Alaska Native	3.1
Asian	1.0
Black or African American	13.9
Hispanic/Latino	2.7
Native Hawaiian & Other Pacific Islander	0.0
White	79.6
Other	1.7
Prefer not to answer	2.0
Area of Service or Support You Provide	
Behavioral	46.6
Education	51.7
Employment/Vocational	43.9
Family support	42.5
Healthcare	23.1
Residential	25.2
Transportation	26.9
Other	22.1

Variable	%
Ages of the Individuals You Serve	
Infants (under 2)	26.9
Children (2-12)	43.5
Youth (13-18)	42.5
Young Adults (19-25)	63.3
Adults (25-64)	67.3
Older Adults (65+)	67.3
Types of Disabilities of the Individuals You Serve^a	
Autism spectrum disorder	69.7
Deaf-blindness	39.5
Deafness	40.8
Developmental delay	68.7
Hearing impairment	56.5
Learning disability	61.6
Intellectual disability	73.1
Mental illness, mental health disorder, or EBD	67.3
Other health impairment or ADD/ADHD	51.7
Physical disability	63.9
Speech/language impairment	59.9
Traumatic brain injury	41.8
Visual impairment	49.7
Substance abuse disorder	28.6
Type of Community in Which You Work^a	
Rural	70.7
Suburban	63.6
Urban	50.0
Do You Work in Multiple Counties?	
Yes	65.8
No	34.2

^aMore than one option could be selected.

Table A7. State Agency Staff Demographics (N = 212)

Variable	%
Age	
Under 20	0.0
20-29	5.7
30-39	22.6
40-49	22.6
50-59	26.4
60-69	16.5
70 or older	3.8
Prefer not to answer	2.4
Sex	
Female	85.8
Male	12.3
Intersex	0.0
Prefer not to answer	1.9
Ages of the Individuals You Serve	
Infants (under 2)	22.6
Children (2-12)	27.8
Youth (13-18)	52.4
Young adults (19-25)	77.8
Adults (25-64)	75.0
Older adults (65 and above)	62.7
Race/Ethnicity	
American Indian and Alaska Native	1.9
Asian	0.5
Black or African American	13.7
Hispanic/Latino	3.3
Native Hawaiian & Other Pacific Islander	0.5
White	78.8
Other	0.0
Prefer not to answer	3.8
Type of Community in Which You Work^a	
Rural	83.0
Suburban	51.4
Urban	46.2

^aMore than one option could be selected.

Variable	%
State Agency	
Commission of Indian Affairs	0.0
Commission on Aging and Disability	3.8
Department of Children's Services	1.9
Department of Correction	0.0
Department of Economic and Community Development	0.0
Department of Education	1.4
Department of Health	10.4
Department of Human Services/Vocational Rehabilitation	50.9
Department of Intellectual and Developmental Disabilities	16.5
Department of Labor and Workforce Development	0.9
Department of Mental Health and Substance Abuse Services	0.5
Department of Personnel	0.0
Department of Veterans Services	0.0
Department of Transportation	0.0
Division of TennCare	0.0
Higher Education Commission	0.0
Human Rights Commission	0.0
Student Assistance Corporation	0.0
Other	11.8
Types of Disabilities of the Individuals You Serve^a	
Autism spectrum disorder	75.9
Deaf-blindness	59.9
Deafness	56.1
Developmental delay	76.4
Hearing impairment	70.3
Learning disability	77.4
Intellectual disability	82.5
Mental illness, mental health disorder, or EBD	81.6
Other health impairment or ADD/ADHD	69.3
Physical disability	83.0
Speech/language impairment	76.9
Traumatic brain injury	70.3
Visual impairment	73.1
Substance abuse disorder	47.6
Other	6.1

Table A8. Healthcare Worker Demographics (N = 89)

Variable	%
Age	
Under 20	0.0
20-29	13.5
30-39	30.3
40-49	27.0
50-59	14.6
60-69	13.5
70 or older	0.0
Prefer not to answer	1.1
Sex	
Female	82.0
Male	18.0
Prefer not to answer	0.0
Race/Ethnicity	
American Indian and Alaska Native	3.4
Asian	4.5
Black or African American	9.0
Hispanic/Latino	0.0
Native Hawaiian & Other Pacific Islander	1.1
White	76.4
Other	0.0
Prefer not to answer	5.6
Your Role	
Physician	16.9
Nurse	25.8
Physician assistant	1.1
Dentist	1.1
Psychologist	7.9
Clinical social worker	1.1
Other	46.1
Practice Setting	
Solo practice	9.0
Private group practice	41.6
Academic medical center	18.0
Federally qualified health center	6.7
Other	28.1

Variable	%
Age of Patients	
Infant (under 2)	47.2
Children (2-12)	69.7
Youth (13-18)	67.4
Young Adults (19-25)	50.6
Adults (25-64)	40.4
Older Adults (65+)	28.1
Types of Disabilities of the Individuals You Serve^a	
Autism spectrum disorder	69.7
Deaf-blindness	39.5
Deafness	40.8
Developmental delay	68.7
Hearing impairment	56.5
Learning disability	61.6
Intellectual disability	73.1
Mental illness, mental health disorder, or EBD	67.3
Other health impairment or ADD/ADHD	51.7
Physical disability	63.9
Speech/language impairment	59.9
Traumatic brain injury	41.8
Visual impairment	49.7
Substance abuse disorder	28.6
Other	0.0
Type of Community in Which You Work^a	
Rural	18.0
Suburban	50.6
Urban	31.5

^aMore than one option could be selected.

FULL LIST OF RESPONSE AREAS WITH DEFINITIONS FOR OPEN-ENDED QUESTIONS.

Table C1: What is your biggest question or need right now related to disability?	
Area	Definition
Financial assistance	financial planning; help paying for a service, support, or equipment
Finding services	finding local services, high quality services, and/or coordinated services; solutions related to difficulties faced when working with disability-related service providers (e.g., lack of follow-up, difficulty connecting to a person, service provider had limited knowledgeable on topic)
Employment	finding employment opportunities or supports (e.g., job coaching)
Transportation	transportation to activities, appointments, or employment; learning to drive
Respite or in-home medical care	finding short-term caregivers to provide a break for primary caregivers (e.g., family members, loved ones), in-home medical care, or nursing assistance
Medical care	finding doctors or medical providers, addressing medical challenges, medication information, receiving a diagnosis, or medical equipment
Housing	independent or supported living opportunities and programs; finding a roommate
Transition to adulthood	supports or services relating to an individual's transition from young adult to adult (e.g., planning for the future, soft skills development, self-determination, prioritization of age-appropriate services)
Unknown future	concern or worry related to unknowns, such as where their adult child with disabilities will live, who will care for them, how they will access transportation; building a future plan
Mental health services	mental health services and/or providers; crisis services
K-12 school	finding academic-related information or help for school-age children or youth with disabilities (e.g., tutoring, supplemental learning opportunities, virtual learning); information about disability evaluations, special education services, or Individualized Education Plans (IEPs)
Behavior	help with challenging behavior; finding behavior therapy or services
Social skills or opportunities	the development of social communication with peers, providers, and family; finding opportunities to increase social interaction through support groups, social skills groups, making friends, or romantic relationships
Adaptive equipment	obtaining adaptive equipment (ramps, home modifications, etc.)
Coronavirus	information about COVID-19 vaccines or illness
Community access	finding inclusive community events or programs, such as recreational activities, summer camps, and faith communities; accessibility within the community (e.g., physical- ramps, accessible restrooms; sensory- sensory friendly hours, quiet spaces)
Post-secondary education	post-secondary education options (e.g., college, training programs, vocational education); disability services within post-secondary programs

Table C1: What is your biggest question or need right now related to disability?

Area	Definition
Therapy	the need for, inability to find, and/or confusion regarding therapies including physical therapy, occupational therapy, and/or speech and language therapy in a community or school setting
Communication	how an individual communicates; barriers related to communication such as a lack of training or limited access to AAC devices; lack of consistent and meaningful communication between stakeholders
Independence	promoting an individual's independence or autonomy
Basic needs	access to food, clothing, or help with rent and utilities
Eligibility	the ability or inability to access services due to finances, disability type, etc.
Conservatorship	obtaining conservatorship or seeking information regarding legal options surrounding guardianship
Where to start	where to begin when looking for resources, services, or information related to disability in general
Understanding/acceptance	being understood, accepted, and not stigmatized because of their disability
Dental Care	dental services (routine or emergency)
Technology	technology access (devices, internet, etc.) or inability to use technology independently
Early childhood education	finding early childhood education (ECE) or early childhood intervention (EIC) services
Culture	various aspects of an individual/family's culture including a need for translation as a result of language barriers or supporting cultural diversity (e.g., need for specific clothing, meal accommodations, holiday exemptions, etc.)
Safety	safety of an individual with a disability (e.g., safety within community, safety within home)
Childcare or adult day program	out-of-home care for children or adults

Table C2: What type of information or help were you looking for?

Area	Definition
Employment	employment opportunities or support (e.g., job coach)
Medical care	information about doctors, diagnoses, in-home care, medical conditions, medical equipment, and medications
Housing	general housing options; independent or supported living opportunities and/or programs; finding a roommate
Mental health care	mental health services and/or mental health providers; crisis services
Financial Assistance	financial planning; help paying for a service, support, or equipment

Table C2: What type of information or help were you looking for?

Area	Definition
Transportation	transportation to activities, appointments, employment; learning to drive
Disability service system	Supplemental Security Income (SSI), TennCare, or general disability services
K-12 school and learning	academic information or help for school-age children or youth with disabilities (e.g., tutoring, supplemental learning opportunities, virtual learning, tutoring, homeschool); information about special education services and Individualized Educational Plan (IEPs)
Respite care	finding short-term caregivers to provide a break for primary caregivers (e.g., family members, loved ones)
Behavior supports or services	help with challenging behavior; finding behavior therapy or services
Adult services	information or services for adults with disabilities, including long-term care services, future planning, and transition from high school to employment
Legal assistance	legal services or information (e.g., conservatorship, family estate planning)
Post-secondary options	post-secondary educational options; scholarships or financial aid opportunities
Therapies	therapies including speech/language, physical, occupational, feeding
Basic needs	access to food, clothing, or help with rent and utilities
Assistive Technology	assistive technology devices for home, school, or work (e.g., AAC devices, modified vehicle)
Social opportunities	structured groups for socializing or support in making friends
Childcare	childcare (e.g., programs for children or youth with disabilities, afterschool care)
Support groups	support groups for family members, siblings, or individuals with disabilities
Daily living support	assistance with personal care and household chores (e.g., cooking, grooming, dressing)
Dental care	dental services (routine or emergency)
Coronavirus	information about COVID-19 vaccines or illness
Disability evaluation	finding doctors or other professionals to conduct disability evaluations
Leisure and recreational activities	recreational activities for individuals with disabilities, such as sports, exercise, arts etc.
Community events	inclusive community events for children and adults with disabilities (e.g., planned events for youth with ASD); supports for individuals with disabilities to attend community events (e.g., wheelchair accessible venues)
Home modifications	providers and organizations to help with home modifications, such as wheelchair ramps
Advocacy	information about disability rights and supports in school, medical, or employment contexts
Dating and relationships	support related to dating and romantic relationships
Summer camps or programs	summer activities, camps, or programs for individuals with disabilities

Table C3: What (if anything) makes it hard to find the information you need?

Experience	Definition
Difficulty finding information	Information needed is difficult to find
Unsure where to start	Unsure where to go for help, who to ask, or what information they are looking for
Lack of resources	Resources needed are difficult to find or do not exist
Connecting with service providers	Problem connecting with service providers such as getting a call back or finding the right person to contact
Lack of organization	Information and resources are not organized or coordinated among different organizations; information in one place contradicts information in another place
No supports for my location	Lack of resources for rural locations; long travel to needed resources
Misinformation/credibility	Incorrect or out of date information; difficult to discern whether information is credible
Financial issue	Resources are not accessible due to financial or insurance concerns
Lack of specificity	Information found is not specific enough for need
Time commitment	Difficult to find information and resources due to time needed to research and call organizations
Access to technology	Limited access to internet or technology; difficulty navigating technology and searching online
Personal problem	Difficulty based on a specific, personal problem including medical needs, how disability affects individual, or a specific need not represented in another category
Rare disability	Resources difficult to find due to lack of research or information on a rare disability
Accessibility of services	Resources are not physically accessible; online information is not accessible for user; resources are not offered to some stakeholders
Trouble understanding information	Difficult to understand information or resources due to confusing terminology
Ineligible	Person with a disability is not eligible for a resource or support due to age or disability
Feel overwhelmed	Overwhelmed by the amount of information available and number of sources
Coronavirus	Response mentions a problem relating to COVID such as offices closed or connecting with others
Need for social interaction	Difficult to find opportunities for social interaction with peers

FULL LIST OF RESPONSE AREAS WITH DEFINITIONS FOR OPEN-ENDED QUESTIONS.

Table D1: List any specific websites or organizations you visit frequently for disability information.

Type of Website/ Organization	Definition
National disability specific sites	national organization that provides information or support for a specific disability or diagnosis (e.g., Autistic Self-Advocacy Network, National Federation for the Blind)
State agency or program	any state agency, department, commission, or council that supports individuals with disabilities (e.g., Vocational Rehabilitation, Dept. Of Intellectual and Developmental Disabilities, TennCare, TN Dept. of Ed., Transition Tennessee, Tennessee Disability Pathfinder)
Tennessee disability non-profit	state/local website or organization that provide information or support to all individuals with disabilities (e.g., The Arc, Disability Rights TN, etc.)
Social media	online community, support group, or informational and resource page on social media platforms (e.g., Twitter, Facebook, Instagram, Reddit)
National disability non-profit	national organization that provides information or support to all individuals with disabilities (e.g., National Organization of Persons with Disabilities, Job Accommodation Network, Council of Exceptional Children)
Tennessee disability specific sites	state or local organization that provides information or support for specific disabilities or diagnosis (e.g., Autism Tennessee, Down Syndrome Association of Middle Tennessee, Tennessee School for the Deaf)
General search engine	a general internet search or specific search engine like Google
Federal program	websites related to federal government programs or agencies (e.g., social security, Veterans Affairs, Americans with Disabilities Act, Individuals with Disabilities Education Act)
Podcast/YouTube	videos or a specific channel on YouTube; podcast episode or specific show (FatheringAutism, TED Talks)
Other websites	websites that are not disability specific (e.g., 211.org, Wikipedia)
State specific sites	websites or organizations from states other than Tennessee

FULL LIST OF RESPONSE AREAS WITH DEFINITIONS FOR OPEN-ENDED QUESTIONS.

Table E1: Share any other ideas you have for making disability information easier to find.

Suggestion	Definition
Streamline information	information is provided in a way that is focused/selective, easy to understand, and accessible and/or needed information is centralized to one resource (website or one-pager, including specific references to accessing information online)
Personalize resources	provide option to filter information or resources according to circumstance or need (e.g., by disability or diagnosis, geographic proximity or location, payment method or insurance accepted, age or grade, language)
Educating professionals	provide information and/or training to professionals who interact with individuals with disabilities so that they are equipped to provide support or referrals (e.g., teachers, school counselors, therapists, state agency staff)
Connect families	create opportunities or promote existing community-based events, support groups, and organizations that provide disability information and facilitate interaction between families
Talk with real person	ability to talk to someone, in real time, who can provide needed information and resources (e.g., live chat feature, hotline, representative at local events or organizations)
Offer non-internet resources	provide information in a format that does not require access to the internet or technology skills (e.g., printed flyers, pamphlets, brochures disseminated in-person or through mail, attend local/community events)
Involve healthcare professionals	have brochures or pamphlets available in medical offices; educate healthcare professionals so that they can share information with families or refer them to resources
Advertise <i>Pathfinder</i>	use local television, radio, newspapers, billboards or other means to advertise <i>Pathfinder</i> to the public
Improve website navigation	ensure that websites are accessible and resources can be easily found
Connect self-advocates	provide information and opportunities for individuals with disabilities to connect with one another by creating groups or compiling and sharing contact information
Update resources	ensure that resources and contact information are comprehensive and frequently updated
Use social media	connect stakeholders and share information through social media platforms, such as Facebook, Twitter, or Instagram
Create an app	create a mobile app that can be easily accessed by families and students
Provide training for families	host workshops or conferences for parents to learn about information or resources
Use direct email	send information directly to people through email