TENNESSEE DEVELOPMENTAL DISABILITIES NETWORK

2025

STATEWIDE NEEDS ASSESSMENT REPORT

Understanding Needs, Identifying Priorities, and Shaping the Future for Tennesseans with Disabilities

DISABILITY RIGHTS TN

VANDERBILT KENNEDY CENTER

TN Council on Developmental Disabilities

UTHSC CENTER ON DEVELOPMENTAL DISABILITIES

Acknowledgements

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Welcome Letter

Dear Advocates, Partners, and Community Members,

Welcome to the *Tennessee Developmental Disabilities Network Statewide Needs Assessment Report 2025*! This document represents a collective effort by four statewide organizations dedicated to improving services and supports of individuals with disabilities in Tennessee: the Tennessee Council on Developmental Disabilities, Disability Rights Tennessee, the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities, and the UTHSC Center on Developmental Disabilities.

The purpose of this needs assessment was simple but critical: to gather insights directly from people with disabilities, their families, and the professionals who serve them. Your experiences and voices are the foundation of this report and will guide our collective efforts to improve the lives of Tennesseans with disabilities in the years to come.

We understand that navigating services and supports can be challenging, which is why we wanted to reduce survey fatigue and join together to create one comprehensive needs assessment. With your help, we now have a clearer picture of the needs and priorities across the state, which will directly inform the future work of our organizations.

Thank you for your time and contributions. Together, we can build a stronger, more inclusive Tennessee for all.

Sincerely,

Tennessee Developmental Disabilities Network

> [Help is hard to find because of] a DEEP lack of understanding, inclusion, and acceptance of disabilities and the needs of both disabled individuals and their families/caregivers. This then trickles into policy, program design, and interpersonal actions with agencies, businesses, and community members.
>
> *– Parent of a young child with multiple disabilities*

Project Overview

This report presents findings from a statewide community needs assessment conducted by the organizations that make up Tennessee's Developmental Disabilities (DD) Network. United in their commitment to improving services and supports for individuals with disabilities, they carried out this assessment to better understand needs and priorities across the state.

KEY TERMS AND DEFINITIONS

To ensure clarity, it is important to define some key terms used throughout this report:

Our state
Refers to Tennessee, with a focus on the disability community. This includes individuals with disabilities, their families and friends, and the professionals who support them. The term reflects the collective experiences and perspectives of these groups across the state.

Needs assessment
A structured process used to gather information and insights about the challenges individuals with disabilities, their families, and the professionals who support them face. It helps identify areas requiring attention and improvement to better serve the disability community.

Need
Any area of life or activity where individuals require help or support, such as healthcare, education, employment, or community inclusion.

Priorities
The areas identified as most important to address in order to improve the quality of life for people with disabilities and their families.

PURPOSE OF THE NEEDS ASSESSMENT

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) of 1963 established a nationwide network of programs to advance the rights, inclusion and independence of individuals with developmental disabilities. Each state has a DD Network composed of three core partners: State Councils on Developmental Disabilities, University Centers for Excellence in Developmental Disabilities (UCEDDs), and Protection and Advocacy Systems (P&As).

Tennessee's DD Network partners collaborate to fulfill this mission by identifying and addressing systemic barriers and providing services to our state's disability community. To meet the DD Act's requirements, each partner organization updates its five-year work plan based on current data. This joint needs assessment serves as the foundation for those updates by gathering input from individuals with disabilities, their families, and professionals statewide. A coordinated approach ensured that the data collected is comprehensive - reducing the burden on Tennesseans while maximizing the impact of our efforts.

COLLABORATION ACROSS TENNESSEE'S DD NETWORK

In Tennessee, the DD Network is a strong and active collaboration among the Tennessee Council on Developmental Disabilities, Disability Rights Tennessee, the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities, and the UTHSC Center on Developmental Disabilities. Partners meet regularly, serve on each other's boards, and collaborate on initiatives to make Tennessee's service system more inclusive, effective, and responsive to community needs.

USES OF THE REPORT

By pooling their efforts, Tennessee's DD Network partners have created a shared dataset to inform all four partner organizations strategic plans. The findings will shape service design, guide resource allocation, and strengthen policy advocacy across the state. Additionally, this report serves as a valuable resource for the disability community, offering insights into current needs, identifying service gaps, and providing actionable recommendations for improvement.

ACKNOWLEDGING OUR PARTICIPANTS

Tennessee DD Network partners sincerely thank all the Tennesseans who participated in this needs assessment. Your contributions have been crucial in shaping this report and will continue to influence the future direction of disability services in Tennessee.

Approach and Report Structure

DATA COLLECTION METHODS

A mixed-methods approach was used to ensure broad and diverse participation across the state. This approach combined quantitative data obtained through surveys and qualitative data collected from focus groups. A brief overview of each method is provided below.

1. **Needs Assessment Survey**

   The primary method of data collection was a survey, available in both English and Spanish. Three versions of the survey were tailored for specific groups:
   - Individuals with disabilities
   - Family members or loved ones (e.g., parents, siblings, or spouses)
   - Professionals who support individuals with disabilities (e.g., educators, direct service providers, and state agency staff)

   The survey addressed a variety of important topics related to the experiences of individuals with disabilities, including their access to services, available support systems, and perspectives on community inclusion. It was divided into several sections, guiding topics included:
   - Are people getting the support they need in areas that matter most to them?
   - What are the most pressing needs and questions of people with disabilities in our state?
   - What are their opinions on Tennessee's service system?
   - What are their experiences and views on community inclusion?
   - Where do Tennesseans turn for information and resources?

   The survey included both multi-select and Likert-type scale questions for participants to select or rate their responses. Additionally, open-ended questions were included to allow participants to elaborate on their experiences and ideas.

   Each version of the survey addressed the same research questions but was tailored to be more relevant to each respondent group. Participants could complete the survey online, by phone, or by using a paper copy if preferred. This flexibility ensured accessibility for all. Accommodations such as screen reader-friendly documents, text-to-speech, and ASL interpretation videos for each survey question were also available to participants who needed them.

2. **Focus Groups**

   Following the survey, virtual focus groups were conducted with a smaller number of participants-adults with disabilities and family members - who volunteered to take part in a follow-up discussion. These sessions provided an opportunity to reflect on key themes emerging from the survey and explore participants' lived experiences in greater depth. Topics included barriers to accessing support, community inclusion, and other issues impacting daily life for Tennesseans with disabilities.

Each session used a semi-structured format, meaning that while the facilitator had specific topics to cover, participants were encouraged to freely express their thoughts and explore topics in more depth. This approach helped provide greater detail and context to the survey findings.

Sessions were 90 minutes long and held virtually to allow for participation across the state without the need for travel or navigation of unfamiliar environments. To support accessibility, accommodations such as closed captioning, screen reader-compatible materials, and advance access to discussion questions were provided.

DEVELOPMENT OF SURVEY AND FOCUS GROUP QUESTIONS

The development of the survey and focus group questions was a collaborative, multi-phase process designed to ensure that all materials were clear, relevant, and accessible to a diverse audience. This process involved extensive input from individuals with disabilities, family members, professionals, and partner organizations.

The process began with DD Network partners, who helped shape the survey to reflect the critical needs and priorities of Tennessee's disability community. Their input, combined with a review of past public input surveys and current literature, ensured alignment with both lived experiences and national trends.

Core community partners, including members of the Tennessee Council on Developmental Disabilities and Vanderbilt Kennedy Center's Community Advisory Council, participated in multiple rounds of review. Their feedback helped improve accessibility, refine question wording, and ensure that items were meaningful across all groups.

To test the clarity and usability of the tools, pilot sessions were conducted with adults with disabilities, family members, and professionals. Feedback from these sessions informed final revisions to the survey and supported the development of the focus group protocol. The final materials were designed to be inclusive, easy to understand, and grounded in real community experience. The following visual summarizes the key stages of development.

> Actually listen to us. LISTEN TO US. We know ourselves and our needs best, as all people do. Be patient, be kind, be open to criticism and change. Most importantly of all, LISTEN TO US.
>
> *– Young adult with multiple disabilities*

FIGURE 1. PHASES OF DEVELOPMENT

01

Step 1: Initial Input & Literature Review
Input gathered from DD Network partners; reviewed past surveys and relevant research; identified key topics and trends.

02

Step 2: Community Partner Feedback
Multiple rounds of review by community councils focused on accessibility and relevance; refined survey structure and language.

03

Step 3: Pilot Testing
Tested with adults with disabilities, family members, and professionals; feedback gathered on clarity, accessibility, and experience.

04

Step 4: Revisions & Protocol Development
Revisions made to improve clarity and user experience; focus group protocol developed and reviewed for accessibility.

05

Step 5: Final Draft Completed
Final survey and focus group materials approved and prepared for statewide data collection.

Caption: Visual overview of the multi-step process used to develop and refine the survey and focus group protocols.

PARTICIPANT OVERVIEW

A total of 1,496 individual took part in the statewide needs assessment. This group included 322 adults with disabilities, 693 family members, and 481 professionals who support individuals with disabilities.

Inclusion Criteria

To ensure the assessment sample reflected a wide range of perspectives, participants from across the state who met the following criteria were invited to complete the survey:

- At least 18 years old
- Lived or worked in Tennessee
- Had a personal or professional connection to individuals with disabilities

Eligibility was assessed through screening questions at the beginning of the survey. The goal was to gather feedback from a sample reflective of Tennessee's diversity, including different races, ages, disability types, geographic regions, and lived experiences.

Recruitment Methods

To maximize participation and reach diverse communities, the project team collaborated with a broad network of local and statewide disability organizations, agencies, and advocacy groups. These organizations helped share information about the survey through their websites, newsletters, social media, and community events. Recruitment partners included nonprofit organizations, centers for independent living, disability service offices, family support centers, and recreational organizations. Partnering with these groups ensured that the study reached as many individuals as possible, including those from historically underrepresented communities. All survey responses were reviewed to confirm eligibility and to screen out automated or non-genuine submissions.

REPORT ORGANIZATION AND STRUCTURE

This report is structured to clearly communicate the key finding from the surrey and focus groups. It begins with a summary of the most significant results, followed by a more detailed exploration of key topics such as access to services, barriers to support, and community inclusion. The report concludes with a summary of key themes identified across survey sections and reflections aimed at improving services and supports for people with disabilities in Tennessee.

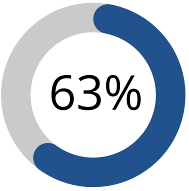
To keep the report focused and manageable in length, the full data sets from the survey are not included in the narrative of each section. Instead, only the most relevant results are discussed here. Complete data sets are available in the appendix for reference.

Because participants could exit the survey at any time, the number of responses varies across sections. Each section of the report notes the total number of responses for context.

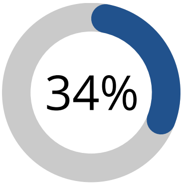
Data Snapshot

The Tennessee Developmental Disabilities (TNDD) Network, a partnership of four statewide organizations, conducted a needs assessment to hear directly from Tennessee's disability community. Nearly 1,500 people participated, including adults with disabilities, family members, and professionals. This snapshot shares some of the most important things we heard. It offers a quick look at how people find help and access support, along with the top five priorities for Tennessee's disability community, illustrated by quotes from participants. Findings from the needs assessment will guide the TNDD Network's work over the next five years, helping all partners focus on what matters most to the disability community. Whether you read the full report or just this snapshot, we hope it sparks thought and leads to action in support of Tennessee's disability community.

How Tennesseans Find and Access Help



Know where to **find information** about disability services.



Have access to the disability services they need.

State Priorities for the Next Five Years

Financial assistance	"With the soaring cost of housing in Tennessee, exorbitant price increases on necessities, and the fact that parents like me have to be able to find jobs with extremely flexible hours, it is very difficult to make ends meet and support yourself financially."
Housing	"[My biggest need is] housing, especially in areas that are safe, affordable, and readily available."
Mental health and wellness	"[My biggest need is] good, RELIABLE, mental health care."
Medical care and therapies	"[My family member's biggest need is] access to therapies, equipment, and resources they need to have happy lives and be able to be involved in society in a way that is beneficial to them."
Advocacy/ self-advocacy	"[Tennessee needs] advocacy that disabled people can be professionals and help society. Finding a good job is hard, due to the fact that employers think we're a liability, or not capable of doing the job properly."

Respondent Profiles

This section provides a high-level summary of the demographic characteristics of survey respondents, highlighting the most relevant and impactful trends across roles. Demographic information was collected at the end of the survey and completed by 1,134 respondents. Full demographic data sets are available in the appendix.

Adults with disabilities and family members were asked to provide information about themselves, including age, gender, race/ethnicity, and the county they live in. They also answered questions about their own disability or, in the case of family members, their loved one's disability. Additional demographic information (e.g., living situation, highest level of education, household income) are available in the appendix.

Professionals were asked about their own demographics (e.g., age, gender, race/ethnicity) and the individuals with disabilities they support (e.g., disability type, county). Additional questions specific to their role – such as age-level served, and years of experience - are presented in the appendix.

ROLE

Survey respondents represented a variety of perspectives, including adults with disabilities, family members, and professionals working in the disability field. All adults with disabilities were over the age of 18 and identified themselves as having a disability. Family members were asked to describe their relationship to the individual with a disability, and professionals were asked to identify their role or field of work. A summary of those roles is presented on the right.

TABLE 1.
REPORTED ROLES OF FAMILY MEMBERS.

Role	Percentage (%)
Parent	87.5%
Spouse or partner	3.0%
Sibling	3.0%
Grandparent	2.2%
Other relative	2.6%
Loved one	1.0%
Other	0.8%

Table 1 displays the roles reported by family members or loved ones. The majority were parents of individuals with disabilities (87.5%), with smaller groups identifying as siblings, grandparents, or spouses/partners. A few respondents selected "other" and described roles such as conservator or niece.

TABLE 2.
REPORTED ROLES OF PROFESSIONALS.

Role	Percentage (%)
Disability organization/ non-profit staff	28.5%
State agency staff	19.9%
Direct service provider	13.0%
Educator	12.7%
Healthcare or therapy provider	12.7%
Other	13.2%

Table 2 displays the roles reported by professionals. A wide range of roles within the disability service system were represented. The largest group worked for disability organizations or non-profits (28.5%), followed by state agency staff (19.9%) and direct service providers (13.0%). Some respondents selected "other" and described roles such as attorney, case manager, certified peer recovery specialists (CRPS), early interventionist, research staff, and government official.

AGE

TABLE 3. AGE OF SURVEY RESPONDENTS BY ROLE.

Group	Average Age	Age Range
Adults with disabilities	43.2	18-78
Family members	49.8	19-85
Loved ones with disabilities	21.7	1-96
Professionals	48.1	22-78

Table 3 displays the average age and age range of adults with disabilities, family members, their loved ones with disabilities, and professionals.

GENDER

FIGURE 2. GENDER OF SURVEY RESPONDENTS BY ROLE.

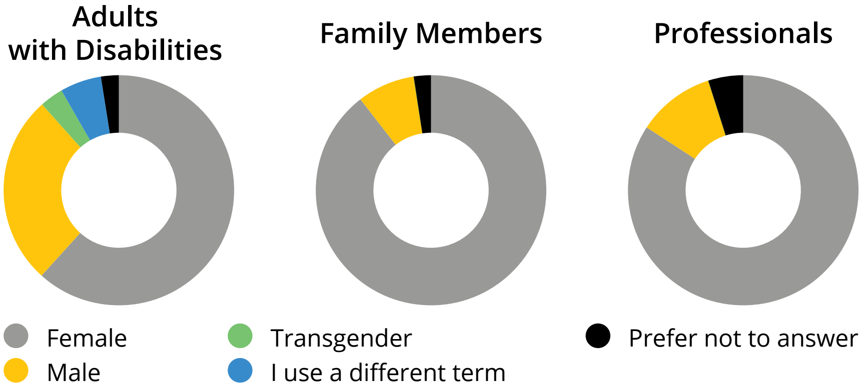


Figure 2 displays the gender breakdown for adults with disabilities, family members, and professionals. The majority of respondents across all groups identified as female.

RACE/ETHNICITY

TABLE 4. RACE/ETHNICITY OF SURVEY RESPONDENTS BY ROLE.

Race/Ethnicity	Adults with Disabilities	Family Members	Professionals
American Indian or Alaska Native	4.6%	1.4%	2.1%
Asian	2.5%	1.8%	2.1%
Black or African American	12.0%	8.1%	8.3%
Hispanic or Latino	2.5%	3.4%	1.6%
Native Hawaiian & Other Pacific Islander	0.8%	0.2%	0.5%
White	81.3%	84.6%	82.3%
Other	5.4%	2.6%	2.1%
Prefer not to answer	5.4%	4.2%	4.9%

Table 4 displays the racial and ethnic identities of respondents. Participants could select more than one option, and some chose “prefer not to answer” or described their identity using open-ended responses.

LOCALE

Survey respondents represented a variety of geographic regions and community types. Adults with disabilities and family members were asked to identify the county they live in and describe their community. Professionals were asked to share the county they primarily work in and describe the type of community where the individuals they support live.

FIGURE 3. REGION OF TENNESSEE BY ROLE.

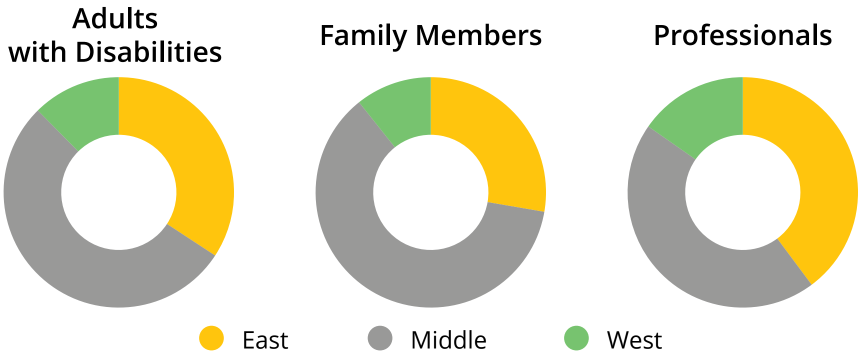


Figure 3 presents the region of Tennessee where respondents live or work. The majority of respondents across all groups were located in Middle Tennessee.

FIGURE 4. COMMUNITY TYPE BY ROLE.

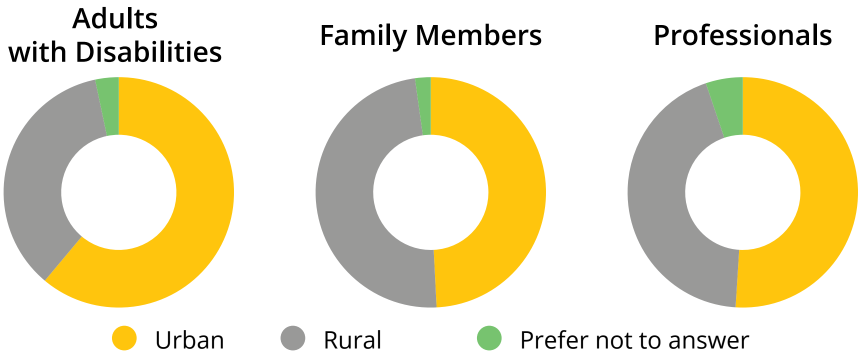


Figure 4 presents the type of community where respondents live or work. There was a relatively even distribution between urban and rural communities, with slightly more adults with disabilities living in urban areas.

NOTE ON REPRESENTATION:
While efforts were made to reach individuals from diverse racial, ethnic, and geographic backgrounds, the majority of respondents across all roles identified as white and lived in East or Middle Tennessee. Future outreach efforts may benefit from additional strategies to increase representation from racially and geographically diverse communities to help ensure that findings reflect the full range of experiences across the state.

DISABILITY

Survey respondents represented a wide range of disabilities. Adults with disabilities were asked to select the label(s) that describe their own disability, and family members were asked to select those that describe their loved one. Professionals were asked to indicate the disabilities experienced by the individuals they support.

FIGURE 5. DISABILITY BY ROLE.

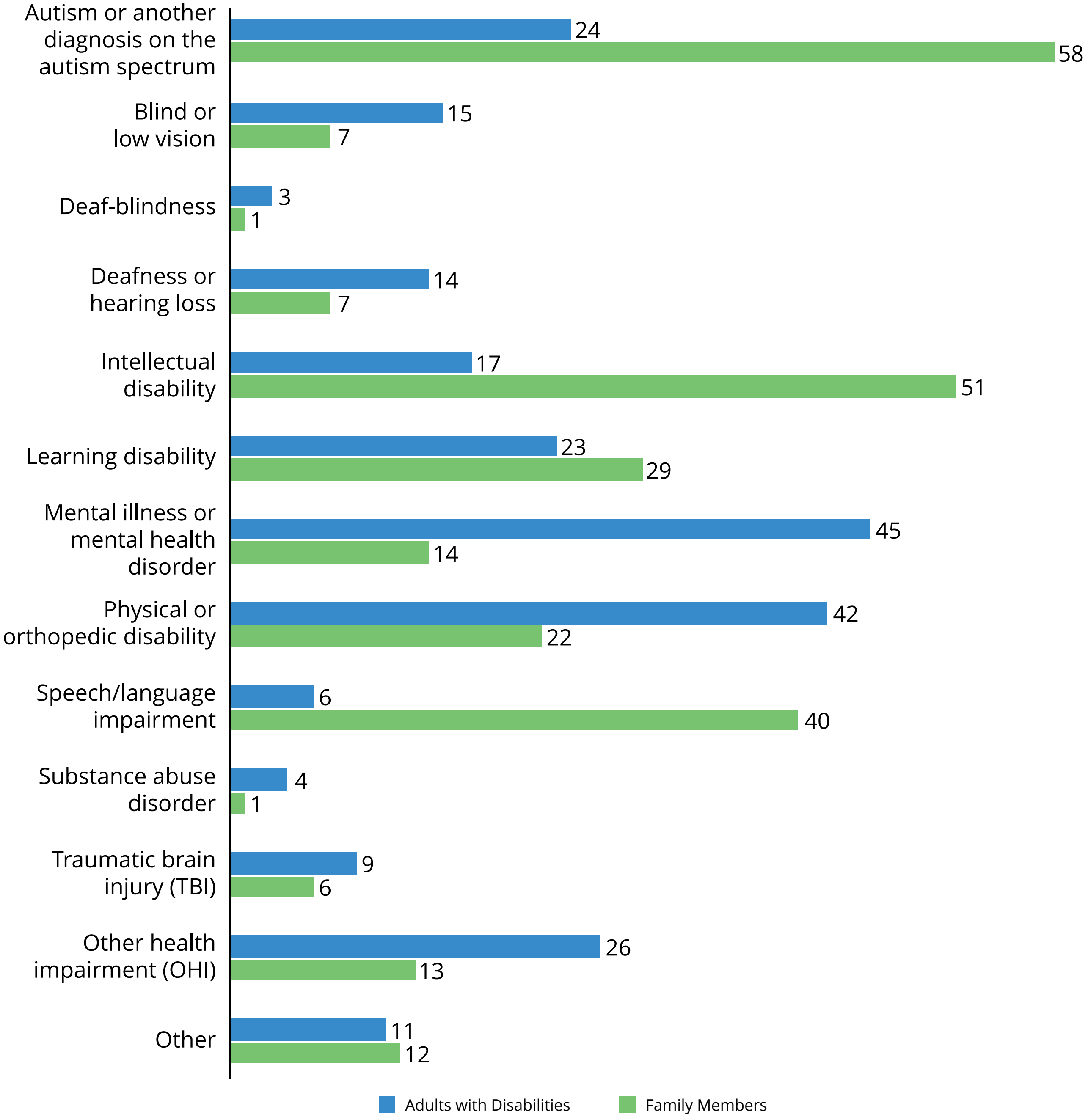


Figure 5 presents the types of disability reported by respondents. Participants could select more than one option. A complete list of answer options, including write-in responses, is available in the appendix.

Key Areas of Life and Their Importance

This section summarizes responses from 988 participants who answered questions about what matters most to them or their family member with disabilities. Adults with disabilities and family members were asked to rate the importance of various areas of life. Their responses helped personalize the survey experience, ensuring participants were only asked follow-up questions relevant to their current life experience.

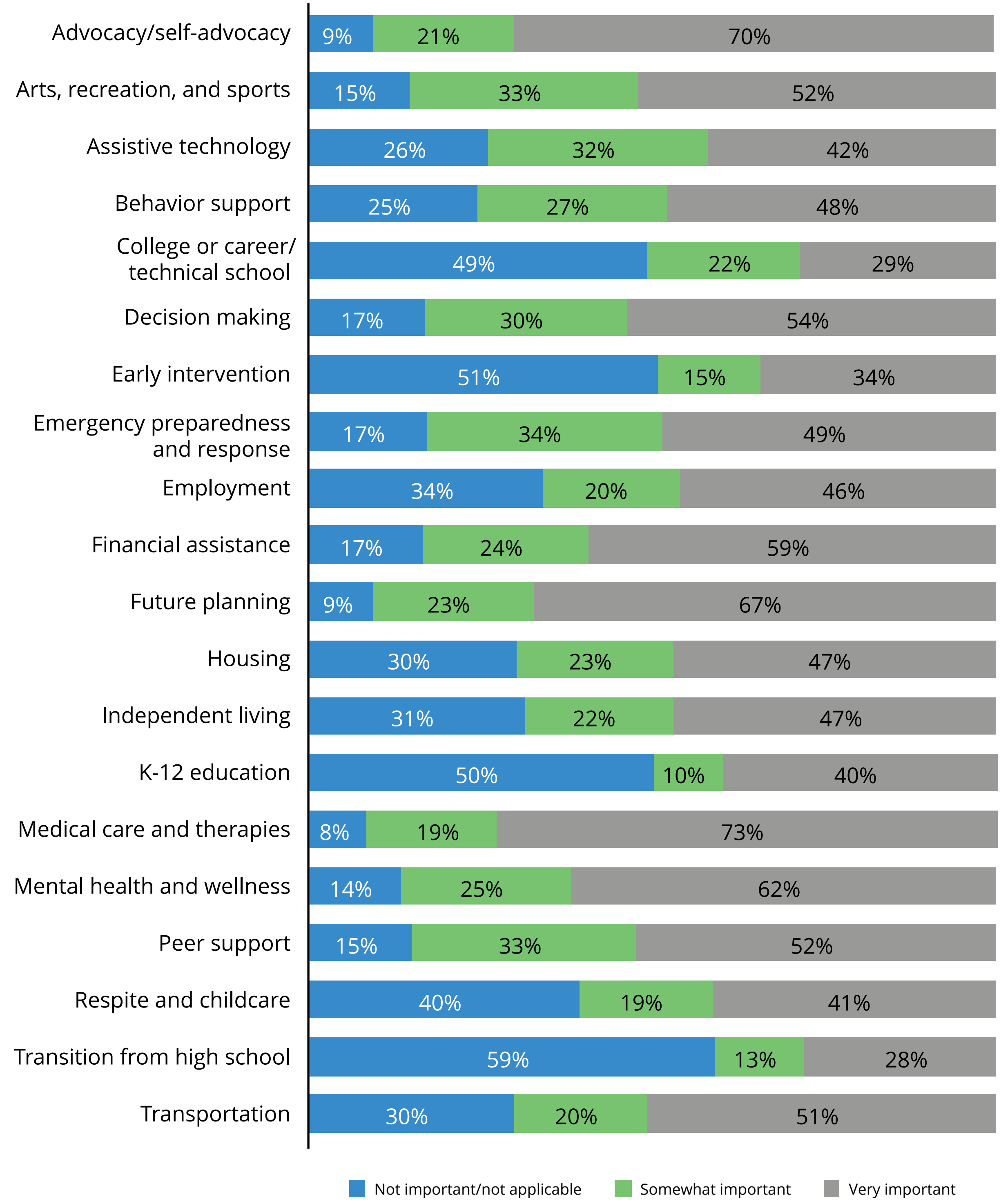
Participants were presented with a list of 20 areas of life that may be valued by anyone in the community. They were asked, "How important is each of these areas to you (or your loved one with disabilities) now?" They rated each area using a three-point scale: *not important/not applicable, somewhat important,* or *very important*. Definitions for each area of life are provided in the appendix. These same areas were referenced throughout the rest of the survey. Participants were only asked follow-up questions about the areas of life they rated as important.

Responses in this section serve as a foundation for identifying which aspects of life matter most to Tennesseans with disabilities and their families. This information can guide decisions about statewide priorities and help target resources and supports where they are most needed.

The following figure presents ratings of each area of life by all respondents. A table follows, highlighting the highest- and lowest-rated areas for each group (adults with disabilities and family members). These visuals offer a snapshot of shared and differing priorities across roles. Key findings are also summarized in the text. A full breakdown of responses by role included in the appendix.

> Tennessee is acknowledging that mental illness is a huge factor in wellness. I know they are looking at it, but they need to do more and provide more funding.
>
> *– 32-year-old with multiple disabilities*

FIGURE 6. IMPORTANCE RATINGS OF KEY AREAS OF LIFE.



Seventeen of the 20 areas of life were rated as *somewhat* or *very important* by the majority of survey respondents. The highest-rated areas across the full sample were medical care and therapies, future planning, and advocacy/self-advocacy. While K-12 education, early intervention, and transition from high school received the lowest importance ratings with fewer than 50% of respondents rating them as *somewhat* or *very important*.

RESULTS BY ROLE

TABLE 5. IMPORTANCE RATINGS OF KEY AREAS OF LIFE BY ROLE.

	Adults with Disabilities	Family Members
Highest-Rated Areas*	• Advocacy/self-advocacy (97.2%) • Mental health and wellness (94.9%) • Medical care and therapies (94.3%)	• Medical care and therapies (90.4%) • Future planning (90.1%) • Advocacy/self-advocacy (87.4%)
Lowest-Rated Areas**	• Transition from high school (55.0%) • Respite and childcare (52.7%) • K–12 education (51.0%)	• Transition from high school (61.1%) • Early intervention (59.5%) • College or career/technical school (57.0%)

*percent rated as *somewhat* or *very important*
** percent rated as *not important* or *not applicable*

Both adults with disabilities and family members rated advocacy/self-advocacy and medical care and therapies with high importance. Adults with disabilities also rated mental health and wellness as highly important, while families emphasized the importance of future planning.

Across both groups, the lowest-rated areas were related to education and caregiving supports at different stages of life. Adults with disabilities most often rated K-12 education, respite and childcare, and transition from high school as *not important* or *not applicable*. Family members similarly gave lower ratings to early intervention, college or career/technical education, and transition from high school.

On average, adults with disabilities rated 15.6 areas as important, indicating they place significant value on multiple aspects of life. On average, family members rated 13.9 areas as important, showing that most family members prioritize a majority of the 20 areas, though slightly fewer than adults with disabilities.

WHY SOME AREAS WERE NOT RATED AS IMPORTANT

Respondents who marked any area of life as *not important* were asked to share why in an open-ended question. Their responses reflected a range personal, practical, and contextual factors. Some had already met the need (e.g., secured housing or employment), while others said certain areas were not relevant due to stage of life or disability- or condition-specific factors. Personal values, financial limitations, and caregiver strain also shaped how priorities were determined. A few respondents noted barriers such as lack of access or available services, and some viewed needs as interconnected (e.g., one area addresses or supports multiple aspects of life).

KEY POINTS AND IMPLICATIONS

This section explores the areas of life that individuals with disabilities and their families prioritize, revealing how these priorities evolve over time and vary based on stage of life and role. The findings emphasize the need for a responsive, person-centered approach to service delivery. Key takeaways include:

- Health and future planning are highly prioritized. Medical care, future planning, and advocacy/self-advocacy were consistently rated as highly important, indicating these are key focus areas for both individuals with disabilities and their families.
- Priorities shift based on life stage. Lower importance ratings for areas like K-12 education, early intervention, and transition from high school reflect that many respondents may have moved beyond these stages or found them less relevant to their current needs.
- Adults with disabilities and families share some priorities but differ in others. While both groups emphasized medical care and advocacy, adults prioritized mental health more, while families focused more on future planning. This suggests support systems should reflect both shared and unique priorities.
- ‘Not important’ does not always mean ‘not needed.’ Many respondents explained that areas they rated as not important were either already addressed or not applicable to their current situation, showing the value of flexible and personalized support planning.
- Context matters in identifying needs. Responses reveal that importance ratings are shaped by factors like stage of life, access to services, financial resources, and personal values, emphasizing the need for personalized approaches in policy and program design.

> “Medicaid has been the biggest help in our case. My son has had numerous medical treatments throughout his life that I wouldn’t be able to pay for if it weren’t for Medicaid and SSI.”
>
> *– Family member of a young child with multiple disabilities*

> “To be perfectly honest, all of [my son’s] needs are currently being met. However, as he continues to age- as myself and my husband-that can and WILL change.”
>
> *– Parent of adult with Down syndrome and mental health* needs

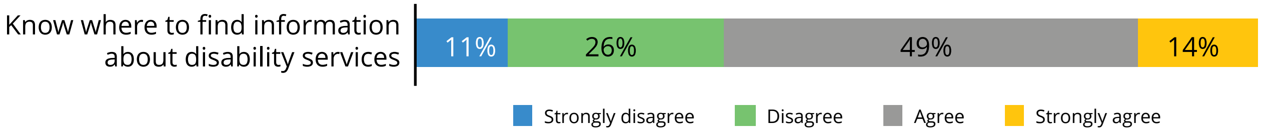
Experiences Accessing Help

This section explores the experiences of 1,496 participants who completed survey questions about accessing disability-related information and support. Input was gathered from all three groups: adults with disabilities, family members, and professionals. Each group was asked about their experiences finding both information and the help they need.

To better understand how people seek and access support, participants responded to two key prompts. The first was a statement: “I know where to find disability information,” rated on a scale from *strongly disagree* to *strongly agree*. The second was a question, “Overall, how easy is it for you to find the help you need?” with response options ranging from *very hard* to *very easy*. The wording of this question varied slightly by role. Family members were asked about finding help to support their loved one with a disability, while professionals were asked about finding help to support the individuals with disabilities they serve.

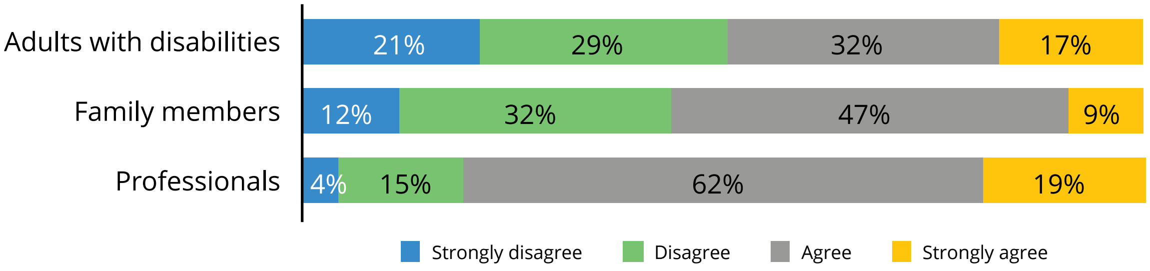
The following figures present the overall ratings for these prompts, as well as how responses varied across the three groups. Additionally, a table highlights commons barriers to accessing help. Key findings are summarized in the text, and a full breakdown of responses to the open-ended question about barriers is available in the appendix.

FIGURE 7. EXPERIENCES FINDING INFORMATION.



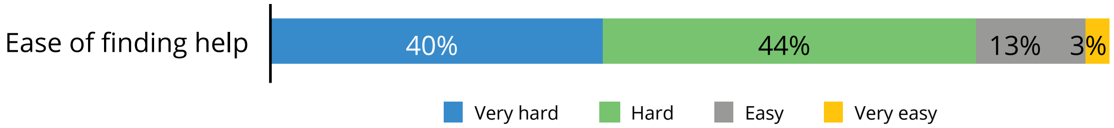
A majority of respondents (63.3%) *agree* or *strongly agree* with the statement “I know where to find disability information.” However, 36.7% of respondents either *disagree* or *strongly disagree*, indicating that a considerable portion of Tennesseans are not confident in their ability to locate the information they need.

FIGURE 8. EXPERIENCES FINDING INFORMATION BY ROLE.



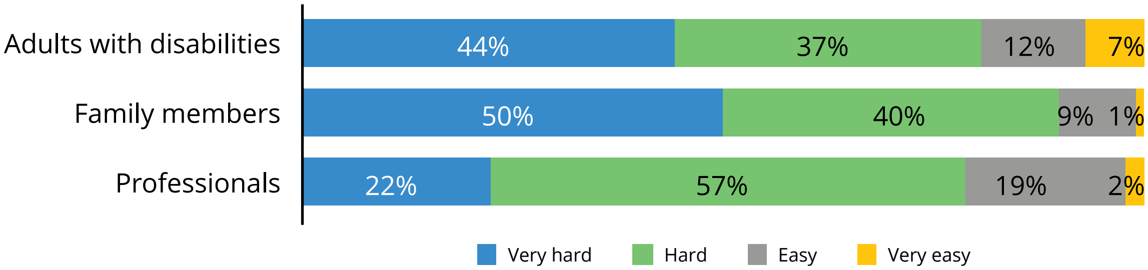
While a majority of respondents indicated confidence in knowing where to find disability-related information, there were noticeable differences across the three groups. Professionals reported the highest levels of confidence in accessing information, with 81% agreement. In contrast, half of adults with disabilities indicated they either *disagree* or *strongly disagree*. This discrepancy highlights potential barriers that adults with disabilities face accessing information. Family members' responses fall in the middle, suggesting they are more likely to be familiar with disability information than adults with disabilities themselves.

FIGURE 9. EXPERIENCES FINDING HELP.



A significant proportion of respondents (83.8%) reported difficulty in accessing help, with 39.5% indicating that it was *very hard* and 44.3% saying it was *hard*. Only 13% felt that finding help was *easy* or *very easy*.

FIGURE 10. EXPERIENCES FINDING HELP BY ROLE.



There was a clear contrast between the ease of finding help and the ease of finding information. While most respondents reported knowing where to find disability information, a significant portion find it difficult to access the help they need. The responses indicate that while awareness of resources is relatively high, navigating the system to secure these resources is a different matter. Adults with disabilities and family members, in particular, experience greater challenges in finding the help they need. Professionals, on the other hand, face fewer difficulties, but still report challenges that may stem from systematic issues.

BARRIERS TO FINDING HELP

TABLE 6. BARRIERS TO FINDING HELP.

	Definition	Quotes
Lack of qualified providers	Support providers who are adequately trained, knowledgeable, and experienced working with individuals with disabilities	“There are no providers with the skill set to work with individuals who engage in extreme behavior outbursts. This has caused our family to become isolated and cut off from the community. We can’t go away, no one visits, going anywhere is challenging and risky because behaviors occur at any time.”
Lack of direct service providers	Professionals who provide personalized care to individuals with disabilities, supporting their daily needs and promoting independence	“The agencies that are trying to staff assistant positions are dealing with a very small pool of people. Very few are truly qualified, and many will leave even before finishing training.”
Challenges accessing and managing benefits	Issues related to obtaining or effectively managing financial assistance and healthcare programs offered by state or federal agencies.	“There are so many layers of assistance, and the state has multiple programs. If you’re enrolled in this one then you can’t have that one...There are three separate programs [my son] would qualify for, but he can’t be in all of them. Choosing one means giving up some benefits that are only offered through the other. It’s very difficult to know if you’re making the right decision.”

To better understand the challenges Tennesseans encountered accessing the help they need, respondents were asked an open-ended follow-up question: “What (if anything) makes it hard to find the help you need?” Responses were reviewed and categorized into three broad themes or barriers: (1) lack of something (e.g., providers or services), (2) systemic issues (e.g., eligibility requirements, complexity of managing care), and (3) information access issues (e.g., accessibility of resources, communication issues with providers). A full list of the 27 barriers identified is available in the appendix.

Table 6 presents the top barriers, including definitions and illustrative quotes. The three most frequently mentioned barriers were a lack of qualified providers, a lack of direct service providers, and challenges accessing and managing benefits.

KEY POINTS AND IMPLICATIONS

This section highlights the challenges individuals face in accessing the help they need, even when information is more readily available. It emphasizes the disconnect between knowledge and practical access to services. Key takeaways include:

- Information is more accessible than help. While most respondents know where to find disability-related information, the large majority still struggle to access the help they need. This indicates a gap between knowledge and access to services.
- Differences in experiences across groups point to unequal access. Adults with disabilities reported the greatest difficulty finding information and help, signaling a need for more inclusive outreach strategies and systems that are more easily navigated by individuals with disabilities.
- Provider shortages remain a core barrier. Lack of both qualified and direct service providers was the most frequently cited obstacle, emphasizing the need for workforce development and improved provider recruitment and retention efforts.
- Complex systems hinder access to benefits. The challenge of navigating overlapping and often conflicting benefit programs suggests the need for system-level reforms and streamlined service coordination.

> “Providers and services change so frequently that it is hard to stay up to date. Needs and resources are so different across the state, that it is hard to support people statewide. You feel like you learn one area well, but then those services change!”
>
> *– Disability organization staff member with 9 years of experience*

> “It takes a lot of research, searching and networking to find opportunities, resources and supports.”
>
> *– Parent of a teen with autism*

> “I have no resources in getting the help I need. I have no idea where to begin or who to reach out to for assistance.”
>
> *– 58-year-old with a physical disability*

Current Support Experiences and Needs

This section summarizes responses from 777 adults with disabilities and family members who shared their experiences accessing help and support. The goal of this survey section was to better understand the types of support Tennesseans with disabilities currently receive and whether those supports are meeting their needs.

Participants responded to two key questions for up to 20 areas of life they had previously identified as important: "What (if any) help do you get in this area?" and "Are your needs met in this area?" Adults with disabilities responded based on their own experiences, while family members answered on behalf of a loved one with a disability.

For each area of life, participants first identified the type of support they received by selecting one of the following options: *no help, informal support, formal support,* or *both informal and formal supports*. These responses helped clarify where informal networks were filling gaps and where formal systems might be falling short.

After identifying the type of support received, participants indicated whether their needs were met in each area by selecting *yes, no,* or *I'm not sure*. To explore barriers to needed help, participants were asked a follow-up question about what might be getting in the way of receiving needed help. This item allowed for multiple responses and participants selected all applicable barriers from a provided list.

The following figures provide a high-level overview of the types of support received and whether needs were met. Key findings are summarized in the narrative, with full results available in the appendix. Responses reflect a wide range of ages and life stages. Family members supported individuals from early childhood through older adulthood. Adults with disabilities were all ages 18 or older, reflecting post-school-age experiences. Due to these differences, results in this section are presented by respondent role.

DEFINITIONS OF SUPPORT TYPES

Informal supports are provided by someone who is not paid for their help, like a family member or friend. These people may help with daily living needs, transportation, medication management, or coordinating care.

Formal supports and services are paid services, often provided by organizations or government funded programs. These include structured supports like day programs, educational services through the school system, and long-term services and support through Medicaid.

SUPPORT TYPES

TABLE 7. TOP REPORTED SUPPORT TYPES IN PRIORITY LIFE AREAS BY ROLES.

	Adults with Disabilities	Family Members
Informal support	• Peer support (33.6%) • Decision making (32.8%)	• Decision making (56.3%) • Advocacy/self-advocacy (53.9%)
Formal support	• Medical care and therapies (29.4%) • Mental health and wellness (23.6%)	• K-12 education (30.5%) • Medical care and therapies (29.9%)
Both types of support	• Medical care and therapies (28.6%) • Mental health and wellness (26.4%)	• Medical care and therapies (37.4%) • K-12 education (35.8%)

Note: "No support" responses are not included in this table, as the survey did not ask participants to clarify whether this meant support was not needed or not available. These responses are discussed in the narrative but are not presented here to avoid misinterpretation.

Adults with disabilities most frequently reported receiving informal supports in areas like peer support and decision making. Formal supports were most common in medical care and therapies and mental health and wellness, while the combination of both formal and informal supports was also most often reported in those same two areas. However, the overall use of both types of support together remained relatively limited.

In contrast, family members more often reported using a mix of formal and informal supports, particularly in areas tied to younger individuals. They most frequently identified informal supports in decision making and advocacy, while formal support was concentrated in K-12 education and medical care and therapies. Use of both types of support was most commonly reported in medical care and therapies and K-12 education.

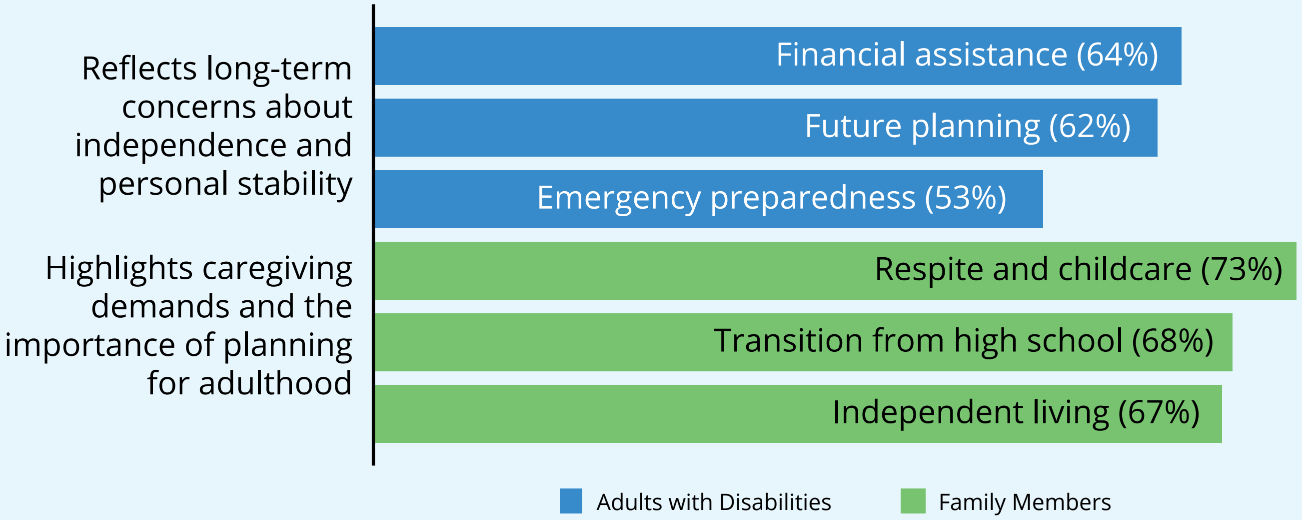
> Either you can find mental health support or support for a disability, but it's difficult to find supports that address the challenges of both.
>
> *– State agency staff with 28 years of experience*

UNMET NEEDS

While participants identified needs in a wide range of areas, several patterns stood out. Adults with disabilities were most likely to report unmet needs related to financial assistance, future planning, and emergency preparedness. These responses reflect concerns about long-term independence, safety, and stability - especially in navigating systems and planning for the future.

Family members highlighted different priorities, with the highest unmet needs related to respite and childcare, transition from high school, and independent living. These areas speak to the ongoing demands of caregiving across the lifespan and the critical need for supports that help individuals move successfully from childhood into adulthood.

AT A GLANCE: UNMET NEEDS BY ROLE



Together, these perspectives underscore the importance of a flexible, lifespan-oriented system of support that addresses both immediate caregiving challenges and longer-term goals for autonomy and stability.

BARRIERS TO ACCESSING SUPPORT

TABLE 8. TOP BARRIERS TO ACCESSING SUPPORT BY ROLE.

Barrier	Adults with Disabilities	Family Members
I do not know where to find help.	**52.3***	38.7
Applying for help is hard or confusing.	**50.5***	**39.6***
The help I need does not exist.	42.8	34.8
I am not eligible to get the help I need.	46.8	26.5
It costs too much.	**53.2***	**40.6***
There are not enough staff.	18.9	**47.3***

*highlight indicates top three barrier per group.

Participants reported a wide range of barriers that prevented them from accessing needed help. For adults with disabilities, the most commonly encountered barriers were not knowing where to find help, difficulty applying for services, and lack of available support. These findings highlight the ongoing challenges of navigating complex service systems and point to a need for better communication, outreach, and system navigation support.

Family members most often cited staffing shortages, cost, and complex application processes as top concerns. These responses reflect the strain on existing service systems, as well as the financial and administrative burdens often placed on families.

The differences across groups suggest that improving access will require both expanding service capacity and simplifying the pathways to get help - especially for people new to services or transitioning between life stages.

FIGURE 11. IN THEIR WORDS: UNMET NEEDS AND SYSTEM GAPS

> Everything has a different system. There is no 'one door' entry, and then it tells you where to go from there.

> Housing and care for my child! What will happen to my child after I die?

> When you are on disability, you can't have savings. So, it's hard to think about what's going to happen when I retire, or what retirement ages are even going to be - I don't know about any of that. It would be nice to be able to plan ahead for savings for if I ever need to be in a nursing home.

> Plans now that he is 18, and what to do when he ages out of public school special education services at 22.

> As parents of a 30-year-old that needs 24-hour care, we are not able to go anywhere without taking him with us. We desperately need resources that can come to the house.

KEY POINTS AND IMPLICATIONS

The findings in this section point to shared concerns as well as role-specific needs. Key takeaways include:

- Support gaps persist across critical life areas, especially during transition periods and in caregiving-intensive areas like respite, childcare, and future planning.
- Unmet needs differ by role, reflecting distinct experiences across the lifespan - adults with disabilities prioritize independence and financial stability, while family members focus on daily caregiving and long-term planning.
- Many participants receive no formal or informal support in essential areas, indicating missed opportunities for early intervention, continuity of care, and coordinated service delivery.
- Navigation barriers are widespread, especially among adults with disabilities. Top barriers include lack of information, confusing application processes, and cost.
- Systemic improvements are needed to build a flexible, responsive support system that is easy to access, adequately staffed, and available across all stages of life.

> “Working with this population requires someone with a lot of compassion and patience. However, when the pay is too low people who are qualified find better paying positions.”
>
> *– Disability organization staff with 3 years of experience*

> “Finances, time, everything is stacked against us! It is more than a full-time job to access disability supports!”
>
> *– Parent of a teen with autism and medical conditions*

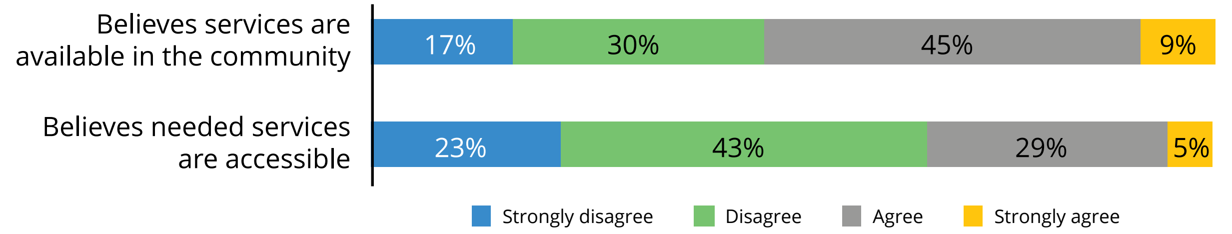
Feedback on State Services

This section explores the experiences of 1,183 participants who completed survey questions about their overall opinions on disability services in Tennessee. Insights were gathered from adults with disabilities, family members, and professionals. The goal of this section was to gain a broad perspective on the availability and accessibility of services statewide – both from those using them and those supporting access.

Respondents were asked to rate their level of agreement with two key statements: (1) Disability services are available in my local community, and (2) I have access to the services I need. The wording was slightly adapted for each group. Family members responded based on their loved one's experience, while professionals answered about the people with disabilities they support. Despite these differences, the statements reflect shared themes about the overall reach and effectiveness of the state's service system.

The following figures provide a snapshot of how participants perceived the availability and accessibility of disability services, both overall and by role. Additionally, a table highlights impactful work at the state level identified by participants. Key findings are summarized in the text, and a full breakdown of responses to the open-ended question is available in the appendix.

FIGURE 12. VIEWS ON STATE SERVICES.



Respondents were more likely to agree that services are available in their local communities than to say they personally have access to the services they need. Nearly three-quarters *agreed* or *strongly agreed* that services are available, but fewer than 35% agreed they could actually access services. This highlights a key gap between service availability and access.

FIGURE 13. VIEWS ON STATE SERVICES BY ROLE.

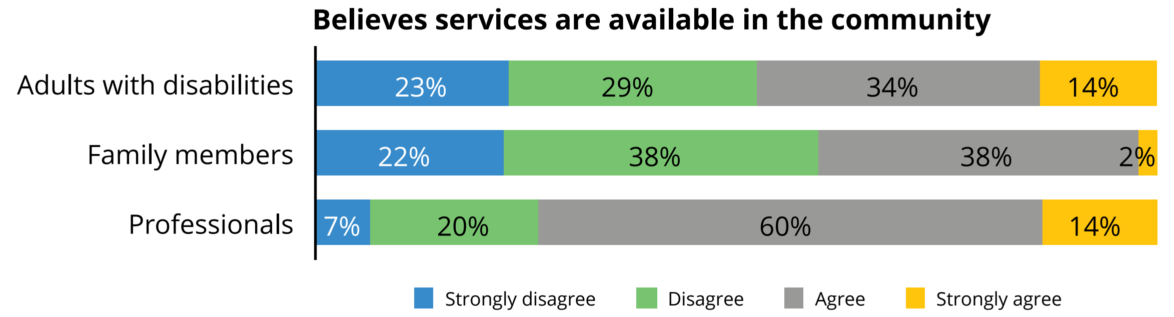
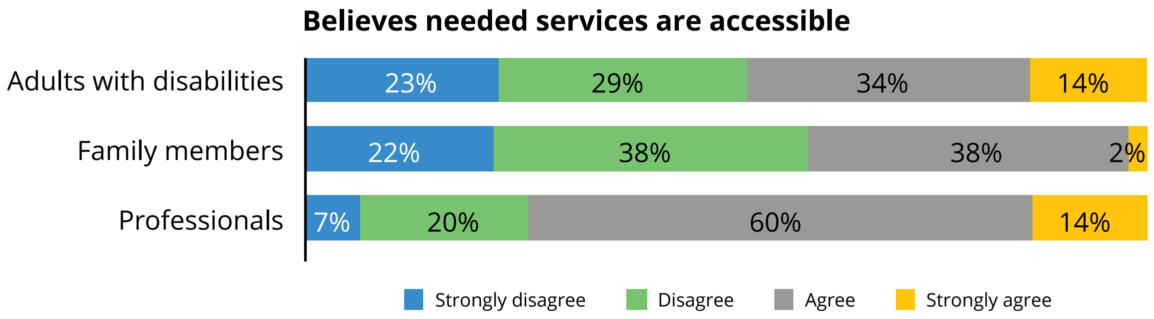


FIGURE 13. VIEWS ON STATE SERVICES BY ROLE.



Professionals were the most likely to agree that services are both available and accessible, followed by adults with disabilities. Family members reported the lowest confidence in service access, particularly regarding whether their loved ones receive the services they need.

MOST IMPACTFUL STATE EFFORTS

To identify areas where the state is making a positive difference in the lives of individuals with disabilities, participants responded to the open-ended question: “What is Tennessee doing now that you think is making the biggest impact for people with disabilities?” Responses were reviewed and categorized into 21 distinct areas of focus. These areas reflect efforts that participants viewed as especially impactful in helping people with disabilities live, work, and thrive in their communities. A full list of all 21 areas is available in the appendix.

TABLE 9. IMPACTFUL WORK IN OUR STATE.

DEFINITION		QUOTES
Employment services	Programs, supports, and policies that help people with disabilities access, obtain, and maintain meaningful work	“ECF CHOICES has made a big difference. Our child has been able to work and get out in the community. The transportation reimbursement has been a life saver when having to use Lyft or Uber.”
Early intervention	Services for infants and young children with developmental delays or disabilities and their families	“Our early intervention program seems to be strong and was crucial in finding the help we do have.”
Katie Beckett Program	A Medicaid waiver program that provides long-term services and supports to individuals with intellectual and developmental disabilities (I/DD), helping them live independently and pursue employment in community settings	“Katie Beckett has been a blessing assisting us with safety devices, communication devices, copay assistance, and tuition for private school.”

Table 9 presents the top three areas most frequently identified by respondents, including definitions and illustrative quotes. Tennessee's most impactful efforts center on employment services, early childhood intervention, and the Katie Beckett Program. These responses highlight initiatives that not only address immediate needs but also support long-term inclusion and independence for people with disabilities across the lifespan.

KEY POINTS AND IMPLICATIONS

The findings in this section reveal persistent gaps between service availability and access, as well as areas where state efforts are making a positive impact. Key takeaways include:

- There is a notable gap between the availability of disability services and individuals' ability to access them, with family members reporting the greatest difficulty.
- Professionals report higher confidence in the system than those directly impacted, suggesting a disconnect between service provision and lived experience.
- Employment services, early intervention, and the Katie Beckett Program were widely recognized as impactful, highlighting the value of programs that promote inclusion, independence, and support across the lifespan.
- Statewide planning should prioritize expanding access, improving communication between providers and families, and scaling up successful programs to reach more people in need.

> It is a full-time job to manage or help a special needs person in the system. You almost need to be the support person, but as a parent, you cannot get paid. So, you need a "real" job to live but if you have a "real" job then you cannot help the disabled person navigate life in a faulty unsupported system.
>
> *– Parent of an adult with multiple disabilities*

> I keep running into dead ends or no one ever contacts me back. It is like I don't have a voice or I'm not important enough.
>
> *– 41-year-old with multiple disabilities*

> [I need] more readily available ways to learn about resources and how to access services that can help me adjust to my disability, build skills, and connect with resources to live independently.
>
> *– 45-year-old with multiple disabilities*

Identifying State Priorities for the Future

This section highlights input from 1,336 Tennesseans—including adults with disabilities, family members, and professionals—who shared their views on the most important statewide priorities. The goal of this section was to explore the areas that respondents believed the state should focus on over the next five years to make meaningful improvements in the lives of people with disabilities. Participants were asked to select five priority areas from a list of 20 previously identified in the survey.

To gain a deeper understanding of the specific needs within these areas, follow-up focus groups were conducted with 50 survey respondents. These conversations helped define what each priority area means to participants and what work is needed to address the challenges they face. Focus groups participants were asked open-ended questions like, "What does financial assistance mean to you?" and "What improvements would you like to see in mental health services?"

The summary below includes a list of identified priority areas, along with key themes and direct quotes that capture the lived experiences and needs of Tennessee's disability community. Additionally, the differences in priorities by role are highlighted, providing a deeper understanding of the unique perspectives of each group. Together, these elements provide a foundation for understanding where the state should direct its attention and resources to improve the quality of life for individuals with disabilities.

STATEWIDE PRIORITIES.

The five statewide priorities most frequently selected by respondents include:

- **Financial Assistance**
- **Housing**
- **Mental Health and Wellness**
- **Medical Care and Therapies**
- **Advocacy/Self-Advocacy**

Financial Assistance

Participants described financial assistance as more than just direct payments or benefits. For many, it includes cash supports or stipends to help covering basic needs, such as housing, food, transportation, and medical expenses. Several participants emphasized the importance of support in navigating and applying for programs like Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI), as well as having trusted individuals who can offer guidance on managing money. Others pointed to the need for funding to access higher education and assistive technology, noting how critical these are for independence and long-term stability. Overall, participants viewed affordability as a foundational issue, connecting nearly every other aspect of life.

Key Themes

- Limited availability of financial assistance programs
- Lack of public awareness or knowledge about available resources
- Narrow eligibility requirements for assistance programs
- Difficulty navigating or applying for financial support programs
- Need for consistent, lifelong financial support – not just short-term or one-time aid
- Financial constraints that limit community participation and independence

> “With the soaring cost of housing in Tennessee, exorbitant price increases on necessities... it is very difficult to make ends meet and support yourself financially.”

> “Beyond the basic needs... [we need] assistance in applying for those programs, which we have a serious lack of in Tennessee.”

> “In Tennessee, funding for people with disabilities is very limited, especially geared towards independent living.”

Housing

Participants defined housing as more than just a place to live—it's about having a safe, stable, and affordable home that supports independence, dignity, and well-being. Many emphasized the importance of being able to live the way they desire, with housing that reflects their personal needs and preferences. For some, housing was also connected to emotional well-being and self-worth. In short, housing was described not just as a basic need, but as a foundation for quality of life and inclusion in the community.

Key Themes

- Limited availability of affordable and safe housing options
- Poor quality or condition of affordable housing
- Strict or narrow eligibility for housing assistance programs
- Discrimination and lack of landlord accountability (e.g., non-compliance with ADA, denial or delay of accommodations)
- Accessibility barriers in housing (e.g., absence of accessible parking, lack of home modifications)
- Need for housing support and planning across a person's lifespan
- Shortage of funding and facilities to support group homes or other supported living options

> It is difficult to secure affordable housing for low-income Tennesseans, especially the disabled, and in low crime neighborhoods.

> There should be better statewide regulations that landlords and people who own property should be held accountable to, so it's not just the person with a disability having to advocate for themselves.

> We have created this system where home and community-based services are supposed to the standard, but we have failed to develop those. We closed shelters and institutions, but where's the replacement? We're 20 years out from those decisions and we've done a terrible job.

Mental Health and Wellness

Participants described mental health and wellness as encompassing a wide range of needs, including access to therapies, diagnoses, and treatment for mental health conditions. While some participants found the term “wellness” vague or overused, they emphasized the real challenges behind it—particularly loneliness, isolation, and emotional strain, both for individuals with disabilities and their caregivers. Mental health was also seen as tied to a person’s beliefs, self-worth, and overall emotional stability. Many highlighted the growing recognition of social isolation as a serious public health issue, underscoring the urgent need for more responsive, inclusive, and person-centered mental health supports.

Key Themes

- Inadequate or lack of insurance coverage for mental health services
- Barriers to care due to diagnosis-based eligibility, insurance restrictions, and limited provider networks
- Shortage of qualified mental health professionals
- Limited availability of mental health facilities and programs
- Inadequate crisis response and limited support during mental health emergencies
- Lack of services for individuals with complex or co-occurring conditions

> “I don’t think insurance is doing enough to support those with mental health needs, whether that be through counseling or even being admitted. I think about patients who go to the emergency room because it’s like the catchall for people who have mental illness of any kind. They get checked out and then it’s rinse and repeat, but they don’t really get taken care of.”

> “As far as needs around mental health, the access is totally dependent on your diagnoses and whether or not you’re insured.”

Medical Care and Therapies

Participants described medical care and therapies as essential to maintaining both physical and mental well-being. One participant shared that medical care means “making sure everything is right with your body so that everything is right with your mind, too.” This quote reflects how closely health, independence, and quality of life are connected. While definitions varied, the discussions emphasized the importance of access to doctors, specialists, therapies, and equipment that are needed by people with disabilities. Participants also spoke about the need for continuity of care, especially when transitioning from pediatric to adult services, and the importance of being treated by providers who understand disability-related needs and communicate with respect and empathy.

Key Themes

- Inadequate or lack of insurance coverage for medical care and therapies
- Restrictive insurance policies and eligibility criteria limiting access to care
- Shortage of healthcare providers, including doctors, therapists, and dentists
- Gaps in care during the transition from pediatric to adult healthcare
- Difficult-to-navigate and unresponsive healthcare systems
- Lack of providers with disability-specific training and expertise
- Lack of integrated, team-based, or coordinated care across services
- Overlooked health needs of caregivers

> There is certainly a gap in the continuum of care from the pediatric to adult transition period. And that is a huge hurdle for everyone across the disability community.

> Medical care is very important. I don’t have coverage. I don’t have any insurance. I have medical bills I have to pay… I think everybody’s entitled to healthcare, whether you have a job or not.

> [Tennessee needs] a statewide education push for all medical personnel—including physicians and hospital staff—on the lives of people with disabilities. This would include issues of conservatorship, quality of life, rights, medications and their impact on health, and even common health issues.

Advocacy/Self-Advocacy

Participants described advocacy as the ability to protect and assert their rights, access reliable information about laws, and effectively communicate their needs. For some, advocacy meant understanding what legal protections exist and what steps to take when those rights are violated. Others highlighted the importance of self-advocacy, describing it as a way to help others understand their experiences, needs, and values. Discussions also touched on the need for education and resources that support advocacy in everyday life. Overall, participants saw advocacy as both a personal skill and a community need, essential for achieving equity and autonomy.

Key Themes

- Limited training, education, or resources for self-advocacy, especially in healthcare settings
- Need to build confidence and skills for effective self-advocacy
- Limited awareness of available advocacy resources and services
- Overreliance on family members for advocacy, with few alternative supports
- Limited access to policymakers and decision-makers

> “It’s not complaining, it’s a concern. It doesn’t affect me only; it affects people around me. So, you have to be specific as far as language sometimes when it comes to being a self-advocate or talking about issues.”

> “[Tennessee needs] more focus on the implementation of person-centered practices for agencies...More training on resources for staff in regards to advocacy and supported decision-making.”

DIFFERENCES IN PRIORITY AREAS BY ROLE

All participants shared their top priorities for the state, but the specific areas selected varied based on their role and lived experience. The following table summarizes the most frequently selected priorities among adults with disabilities, family members, and professionals.

TABLE 10. STATEWIDE PRIORITIES BY ROLE.

Priority Area	Adults with Disabilities	Family Members	Professionals
Housing	✓	✓	✓
Financial Assistance	✓	✓	
Mental Health and Wellness	✓		✓
Advocacy/Self-Advocacy	✓		✓
Employment	✓		✓
Behavior Support			✓
Medical Care and Therapies		✓	
Respite and Childcare		✓	

Housing was the only priority selected across all groups, highlighting a widespread need for safe, affordable, and accessible living options. Financial assistance also emerged as a concern for both adults with disabilities and family members, reflecting ongoing challenges of affording basic needs and navigating benefit systems. Adults with disabilities and professionals prioritized mental health and advocacy, highlighting the importance of empowerment and person-centered support systems. Employment stood out as a key issue for adults with disabilities and professionals, while family members and professionals selected behavior support, medical care, and respite. These patterns reinforce the importance of designing flexible, lifespan-oriented supports that reflect the distinct experiences of each group.

KEY POINTS AND IMPLICATIONS

Findings from this section highlight shared concerns and role-specific priorities. Key takeaways include:

- Housing was the top priority across all roles, underscoring a critical need for affordable, accessible living options and coordinated, system-wide investment.
- Family members emphasized caregiving-related needs, including respite, behavior support, and access to medical care. This highlights the importance of providing reliable, well-coordinated services and funding to help families manage care and reduce stress.
- Adults with disabilities prioritize autonomy, including employment, advocacy, and mental health supports, signaling the importance of centering independence, choice, and inclusion in future planning.
- The variation in priorities across roles demonstrates the need for flexible, person-centered services that adapt to diverse experiences and changing needs throughout the lifespan.

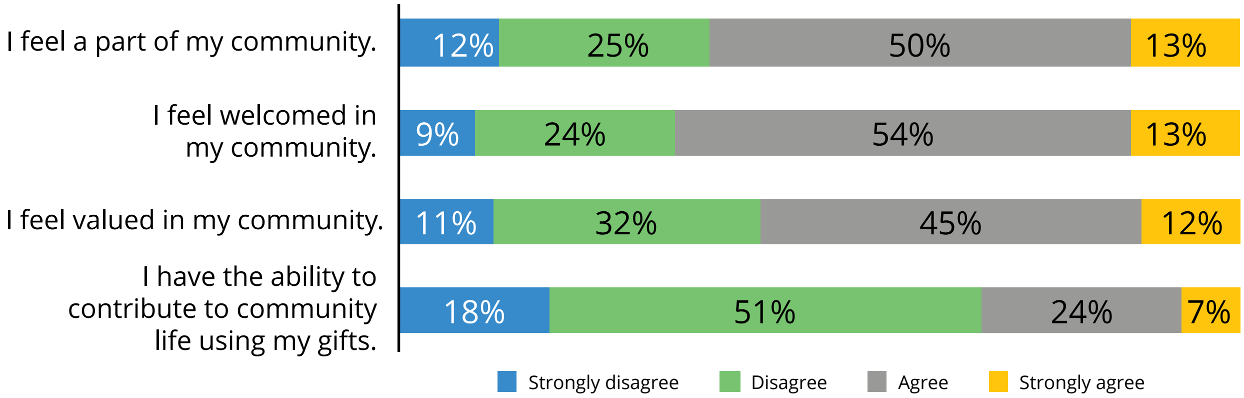
Perspectives on Community Inclusion

This section presents findings from 1,144 participants- including adults with disabilities, family members, and professionals- who shared their views on community inclusion. The goal was to understand how well people with disabilities feel included in their communities and the extent to which they experience a sense of belonging.

Participants responded to six statements related to inclusion, access, and personal connection to their communities. To deepen understanding, follow-up focus groups were conducted with 50 survey respondents. These conversations explored the meaning of belonging and what changes are needed to foster more inclusive environments. Participants responded to questions such as, "What does it mean to belong in your community?" and "What needs to change in places where you don't feel that sense of belonging?"

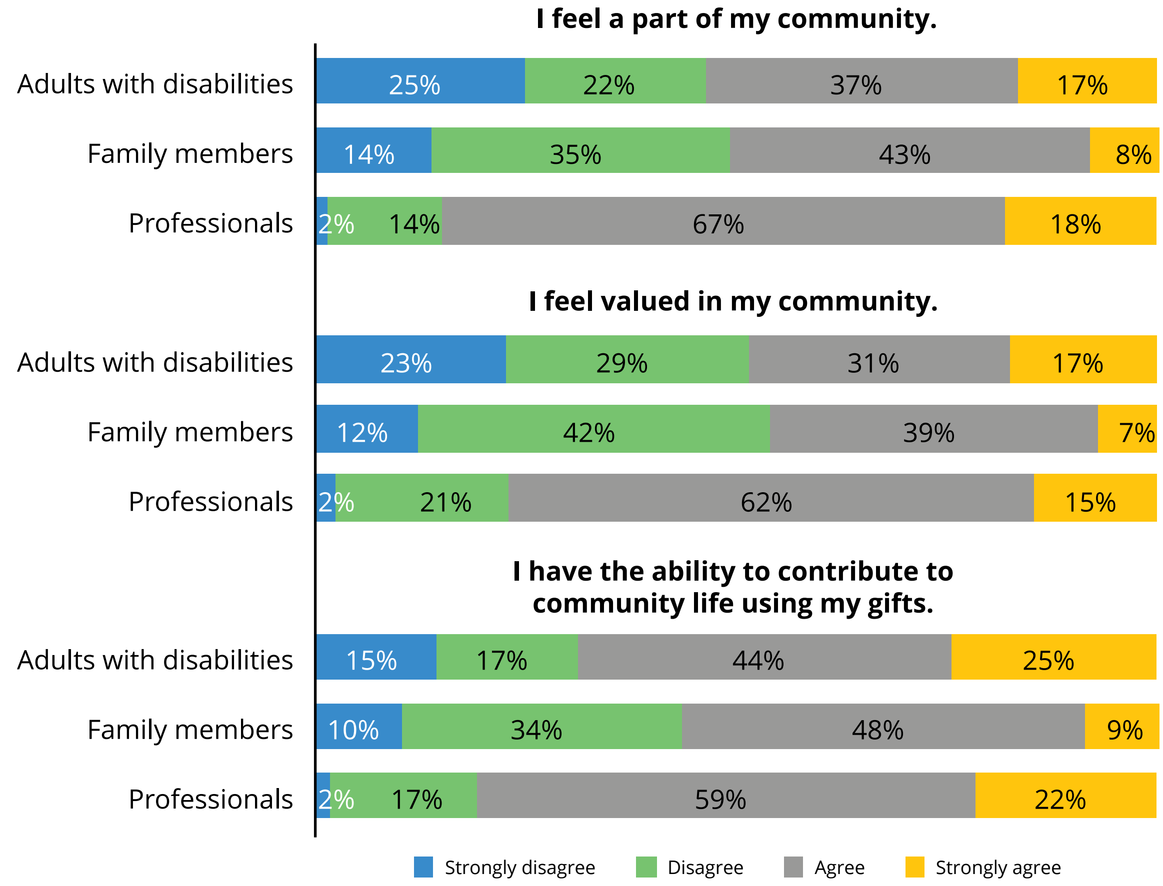
The figures below present selected survey responses for the full sample and by respondent role, highlighting key differences across groups. Additional results are summarized in the narrative and provided in the appendix. Quotes from focus groups are included throughout to provide context and amplify the voices of people with lived experience.

FIGURE 14. PERSPECTIVES ON BELONGING AND CONTRIBUTION IN THE COMMUNITY.



> As a parent of a child with special needs, it's kind of unspoken that [those] are the only people that I should be involved in a community with — people who have children that are similar to my children — that my community should only be that community.

FIGURE 15. PERSPECTIVES ON BELONGING AND CONTRIBUTION BY ROLE.



Responses reflect how personally connected respondents feel to their communities. Adults with disabilities consistently reported lower agreement across all three items compared to professionals. Less than half said they feel a part of or valued in their community, highlighting a sense of social exclusion that many described in focus groups. However, views on contributing to community life were more positive, with the majority of adults with disabilities expressing agreement. This suggests even without a strong sense of belonging; many still recognize their value and potential to give back to their community.

FIGURE 16. PERSPECTIVES ON ACCESS TO COMMUNITY SPACES AND EVENTS.

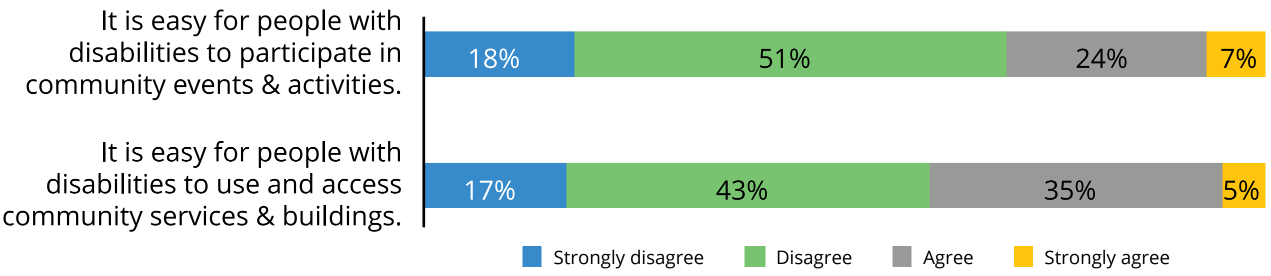
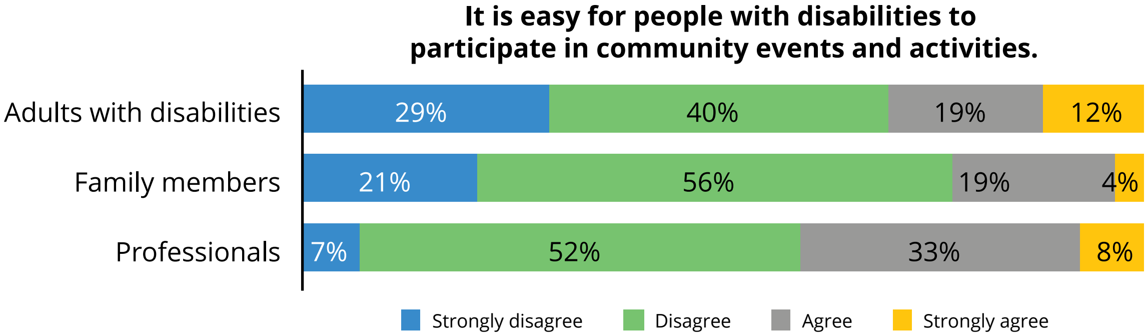


FIGURE 17. PERSPECTIVES ON ACCESS TO COMMUNITY SPACES AND EVENTS BY ROLE



While some respondents agreed that communities are accessible, the data reveals a more negative picture overall, especially among adults with disabilities and their family members. Fewer than one in three adults with disabilities agreed that it is easy to participate in events or access community services and buildings. These results point to ongoing environmental and systematic barriers that can limit full community inclusion.

FIGURE 18. WHAT BELONGING MEANS: VOICE FROM THE COMMUNITY

> I would say belonging, to me, means something like: 'We plan this with you in mind,' versus 'You're welcome to come.'

> The places that we might have a sense of belonging are where people willingly help us and love us for who we are.

> Not being the outsider. Not being the token person with a disability. Not having to educate every time you go through a grocery store line about why you travel with a cane or why your phone talks to you… not having to answer why. Just that it's accepted as a natural part of the community—to have disabilities, to have conditions that need to be accommodated so that you can function.

KEY POINTS AND IMPLICATIONS

Findings from this section reveal meaningful differences in how community inclusion is experienced and perceived. Key takeaways include:

- Adults with disabilities were significantly less likely to feel included, valued, or able to participate in community life, highlighting persistent barriers to genuine belonging. These findings point to the need for inclusive planning that centers the voices of people with disabilities.
- Family members' views often aligned more closely with adults with disabilities than with professionals, especially on questions about access and participation. This suggests that firsthand or caregiving experience with disability shapes how people understand inclusion.
- Professionals were more likely to feel included in their own communities, which may reflect different day-to-day experiences. Creating more opportunities for professionals to listen to and learn from people with disabilities can help inform better community efforts.
- Environmental and social barriers continue to limit full inclusion, with fewer than one in three adults with disabilities agreeing that it's easy to access community events or services. This underscores the need for investment in both physical accessibility and inclusive community norms.
- Belonging was described not just as being welcomed, but as being considered from the start. Moving from reactive accommodations to proactive design is key to building inclusive communities.

Key Findings and Reflections

The following key findings highlight the most pressing issues and themes that emerged throughout the report. These insights emphasize the importance of creating a service system that is flexible, inclusive, and person-centered. Supports must be able to adapt to the unique needs of individuals with disabilities across different stages of life. The findings also reveal persistent barriers in accessing help, as well as gaps in perceptions of inclusion and community participations. Together, these trends point to areas where targeted efforts are needed to improve service delivery, community engagement, and long-term planning for individuals with disabilities and their families.

KEY TAKEAWAYS

Services That Adapt Across the Lifespan

A central theme in this report is the need for services that not only respond to individuals' current needs, but also evolve across the lifespan. People with disabilities and families emphasized both the value of flexible, person-centered approaches and the importance of long-term planning—especially around medical care, financial stability, mental health, and autonomy.

Implication: Service systems should provide coordinated, person-centered supports that adjust over time. This includes helping individuals and families plan for future needs while meeting present-day goals and challenges.

Knowledge vs. Access

Despite many respondents reporting that they knew where to look for information, the majority still struggled to get the help they needed. This gap between awareness and actual access suggests that knowing about resources is not enough. Barriers in navigation, eligibility, and availability persist in our state's service system.

Implication: Resources must be shared in accessible, user-friendly formats. Professionals, including direct service providers and community organizations, should work together to streamline access to information, reduce navigation burdens, and coordinate support.

Perception of Inclusion and Community Participation

Adults with disabilities reported feeling less included and valued in their communities compared to professionals, who were more likely to view their communities as inclusive. This difference in perception highlights the need for increased community engagement and awareness efforts.

Implication: Community engagement should be informed by direct input from individuals with disabili-ties and their families. Training and awareness for professionals, local leaders, and commu-nity organizations can help bridge this gap.

CONCLUSION

This report underscores the need for a service system in Tennessee that is inclusive, responsive, and able to meet the needs of individuals at every stage of life. As the state continues its work to improve supports and systems, these findings should guide policy, funding, and program development. By focusing on person-centered planning, removing barriers to access, and fostering genuine inclusion, Tennessee can build a future where all citizens are valued, supported, and empowered to thrive.

Appendix

The appendix contains full data sets, summary tables, and supplemental materials referenced throughout this report. The materials provided here offer additional context and depth for those interested in exploring the data in more detail.

If citing or sharing these materials, please refer to the suggested citation provided on the Acknowledgements page.

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III EXPERIENCES ACCESSING HELP

IV CURRENT SUPPORT EXPERIENCES AND NEEDS

V FEEDBACK ON STATE SERVICES

VI COMMUNITY PERSPECTIVES

Table A1: Respondent Profiles – Adults with Disabilities

Variable	%
Age	
Average (std dev)	43.2 (14.6)
Range	18-78
Disability type[a]	
Attention-deficit/hyperactivity disorder	38.0
Autism or another diagnosis on the autism spectrum	23.6
Blind or low vision	15.2
Deaf-blindness	2.5
Deafness or hearing loss	13.9
Learning disability	22.8
Intellectual disability	16.9
Mental illness or mental health disorder	45.1
Neurological disabilities	21.9
Physical or orthopedic disability	41.8
Speech/language impairment	5.5
Substance abuse disorder	3.8
Traumatic brain injury	8.9
Other developmental disabilities	6.8
Other health impairment	26.2
Other	11.4
Support to do daily living activities	
No support	12.4
Some support	59.5
A lot of support	21.1
Total support	3.7
Prefer not to answer	3.3
Race	
American Indian or Alaska native	4.6
Asian	2.5
Black or African American	12.0
Native Hawaiian or Other Pacific Islander	0.8
White	81.3
Other	5.4
Prefer not to answer	5.4
Ethnicity	
Hispanic or Latino	2.5
Not Hispanic or Latino	89.1
Prefer not to answer	8.4
Gender Identity	
Female	61.7
Male	26.7
Transgender	3.3
I use a different or more than one term	5.8
Prefer not to answer	2.5
Highest Level of Education	
Some high school	4.6
High school or GED	17.7
Some college	19.8
Certificate	5.9
Associate's degree	8.9
Bachelor's degree	16.5
Master's degree	21.5
Doctoral degree	2.1
Prefer not to answer	3.0
Marital Status	
Single	50.2
Married/living with partner	26.8
Separated/divorced	14.6
Widowed	4.2
Prefer not to answer	4.2
Employment Status	
Yes	50.6
No, but I want to be	29.6
No, and I do not want to be	11.6
Prefer not to answer	8.2
Living Situation	
My own home or apt	53.7
Home or apt with family	32.6
Home or apt with roommates	5.0
Dorm or military housing	0.8
Group home or other supervised living	0.4
Jail/prison/detention center	0.0
Nursing home	0.0
Psychiatric hospital	0.0
Family model	0.0
Intentional community	0.8
Assisted living	1.2
ICD-ID	0.0
Homeless	2.5
Other	2.1
Prefer not to answer	0.8
Personal Income	
20,000 or less	40.4
20,001 to 40,000	20.4
40,001 to 60,000	12.6
60,001 to 80,000	6.1
80,001 to 100,000	2.2
More than 100,000	3.5
Prefer not to answer	14.8
Community Type	
Urban	61.1
Rural	35.6
Prefer not to answer	3.3
TN Region	
West	12.4
Middle	53.3
East	34.2

[a] More than one option could be selected.

Table A2: Respondent Profiles – Family Members

Family Member (Survey Respondents)

Variable	%
Role	
Parent	87.5
Spouse or partner	3.0
Sibling	3.0
Grandparent	2.2
Other relative	2.6
Loved one	1.0
Other	0.8
Age	
Average (std dev)	49.8 (12.1)
Range	19-85
Race[a]	
American Indian and Alaska Native	1.4
Asian	1.8
Black or African American	8.1
Native Hawaiian & Other Pacific Islander	0.2
White	84.6
Other	2.6
Prefer not to answer	4.2
Ethnicity[a]	
Hispanic or Latino	3.4
Not Hispanic/Latino	90.3
Prefer not to answer	6.3
Gender Identity	
Male	8.5
Female	89.3
Transgender	0.0
Use different term or more than one term	0.0
Prefer not to answer	2.2

Variable	%
Highest Level of Education	
Some high school	1.0
High school or GED	5.7
Some college	14.4
Certificate	4.0
Associate’s degree	8.5
Bachelor’s degree	33.6
Masters degree	24.1
Doctoral degree	6.5
Prefer not to answer	2.2
Household Income	
$20,000 or less	6.8
$20,001-$40,000	9.6
$40,001-$60,000	12.4
$60,001-$80,000	13.0
$80,001-$100,000	12.8
More than $1000	27.7
Prefer not to answer	17.8
Community type	
Rural	49.2
Urban	48.6
Prefer not to answer	2.2
TN Region	
West	10.7
Middle	61.6
East	27.7

[a] More than one option could be selected.

Table A2: Respondent Profiles – Family Members

Loved One with Disabilities

Variable	%	Variable	%
Age		Daily Support needs	
Average (std dev)	21.7 (16)	No support	2.8
Range	1-96	Some support	36.8
Disability type[a]		A lot of support	38.2
Attention-deficit/hyperactivity disorder	29.1	Total support	22.0
Autism or another diagnosis on the autism spectrum	57.9	Prefer not to answer	0.1
Blind or low vision	7.2	Communication Mode	
Deaf-blindness	0.7	Talking	66.6
Deafness or hearing loss	6.7	Using pictures or communication device	5.9
Learning disability	29.3	Sign language or other signs	1.8
Intellectual disability	51.2	Gestures, facial expressions, sounds, or body movements	20.9
Mental illness or mental health disorder	14.0	No intentional communicate with others	4.8
Neurological disabilities	24.2	Living Situation	
Physical or orthopedic disability	22.1	Their own home or apt	12.4
Speech/language impairment	39.9	Home or apt with family	78.3
Substance abuse disorder	0.6	Home or apt with roommates	1.0
Traumatic brain injury	5.5	Dorm or military housing	0.6
Other developmental disabilities	18.4	Group home or other supervised living	2.2
Other health impairment	13.0	Jail/prison/detention center	0.4
Other	11.8	Nursing home	0.6
		Psychiatric hospital	0.1
		Family model	1.6
		Intentional community	0.9
		Homeless	0.1
		Other	1.3
		Prefer not to answer	0.1

[a] More than one option could be selected.

Table A3: Respondent Profiles – Professionals

Variable	%	Variable	%
Role		Race	
Direct Service Provider	13.0	American Indian or Alaska Native	2.1
Disability organization or non-profit staff	28.5	Asian	2.1
Educator	12.7	Black or African American	8.3
Healthcare or other therapy provider	12.7	Native Hawaiian & Other Pacific Islander	0.5
State agency staff	19.9	White	83.2
Other	13.2	Other	2.1
Years in the Field		Prefer not to answer	4.9
Average (std dev)	16.0 (11.9)	Ethnicity	
Range	0-60	Hispanic or Latino	1.6
Stage of Life Supported[a]		Not Hispanic or Latino	91.7
Prenatal or infancy	25.2	Prefer not to answer	6.7
Early childhood	35.1	Gender Identity	
School age	45.4	Male	10.9
Young adult	68.2	Female	84.2
Adult	67.3	Transgender	0.0
Aging	58.5	I use a different term or more than one term	0.0
Disability Label		Prefer not to answer	4.9
ADD/ADHD	71.9	Highest Level of Edu	
Autism	84.1	Some high school	0.0
Blind or low vision	58.6	High school or GED	4.1
Deaf-blindness	36.1	Some college	6.0
Deafness or hearing loss	56.7	Certificate	1.6
Learning disability	71.5	Associate's degree	7.3
Intellectual disability	83.5	Bachelor's degree	34.7
Mental Illness or mental health disorder	69.5	Masters degree	37.8
Neurological disabilities	72.1	Doctoral degree	7.3
Physical or orthopedic disability	68.2	Prefer not to answer	1.3
Speech/language impairment	76.4	Community Served	
TBI	58.2	Rural	51.0
Substance use disorder	31.5	Urban	43.8
Other developmental	56.0	Prefer not to answer	5.2
Other health impairment	44.6	TN Region	
Other	10.1	West	15.3
Age		Middle	44.9
Average (std dev)	48.1 (12.1)	East	39.8
Range	22-78		

[a] More than one option could be selected.

Table A4: Key Areas of Life – Definitions

Area of Life	Definition
Advocacy/self-advocacy	speaking up and taking action to support the rights of people with disabilities.
Arts, recreation, and sports	activities that people enjoy doing in their free time, like art or sports.
Assistive technology	a device, tool, or piece of equipment used to help someone do or access everyday tasks. AT can help someone read better, move more easily, or communicate effectively. Examples include screen reader software, communication devices, and wheelchairs
Behavior support	strategies to handle challenging, inappropriate, or dangerous behavior
College or career/technical school	places you go to learn after high school to get a degree or certificate in an area of interest
Decision making	making choices on your own or helping someone with a disability to make their own decisions
Early intervention	therapy or other support for infants and young children with developmental delays or disabilities
Emergency preparedness and response	steps taken to make sure people are safe, before, during, and after an emergency or natural disaster
Employment	having a paid job
Finanical assistance	funds to help pay for utilities and basic needs, like groceries, clothing, and furniture
Future planning	creating a plan for a person with a disability to help them live as independently as possible. It helps the person identify supports they will need as they age
Housing	options for places to live
Independent living	skills a person needs to live on their own, with or without support. These can include personal care, hygiene, food preparation, or managing money
K-12 education	schools where children go to learn academic, social, and other skills from kindergarten until 12th grade
Medical care and therapies	services to help people get and stay healthy, including doctor’s appointments, dental care, and different therapies
Mental health and wellness	the way you think, feel, and act; actions and lifestyle choices to improve your health and happiness
Peer support	sharing knowledge and ideas with a peer or group of peers who have similar experiences. This can include support groups, meet-ups, or social events
Respite and childcare	temporary rest for a caregiver provided by a qualified person for a short time
Transition from high school	moving or preparing to move from high school to adulthood
Transportation	ways to get from one place to another, such as cars, buses, or trains

Figure A1: Importance Ratings by Role

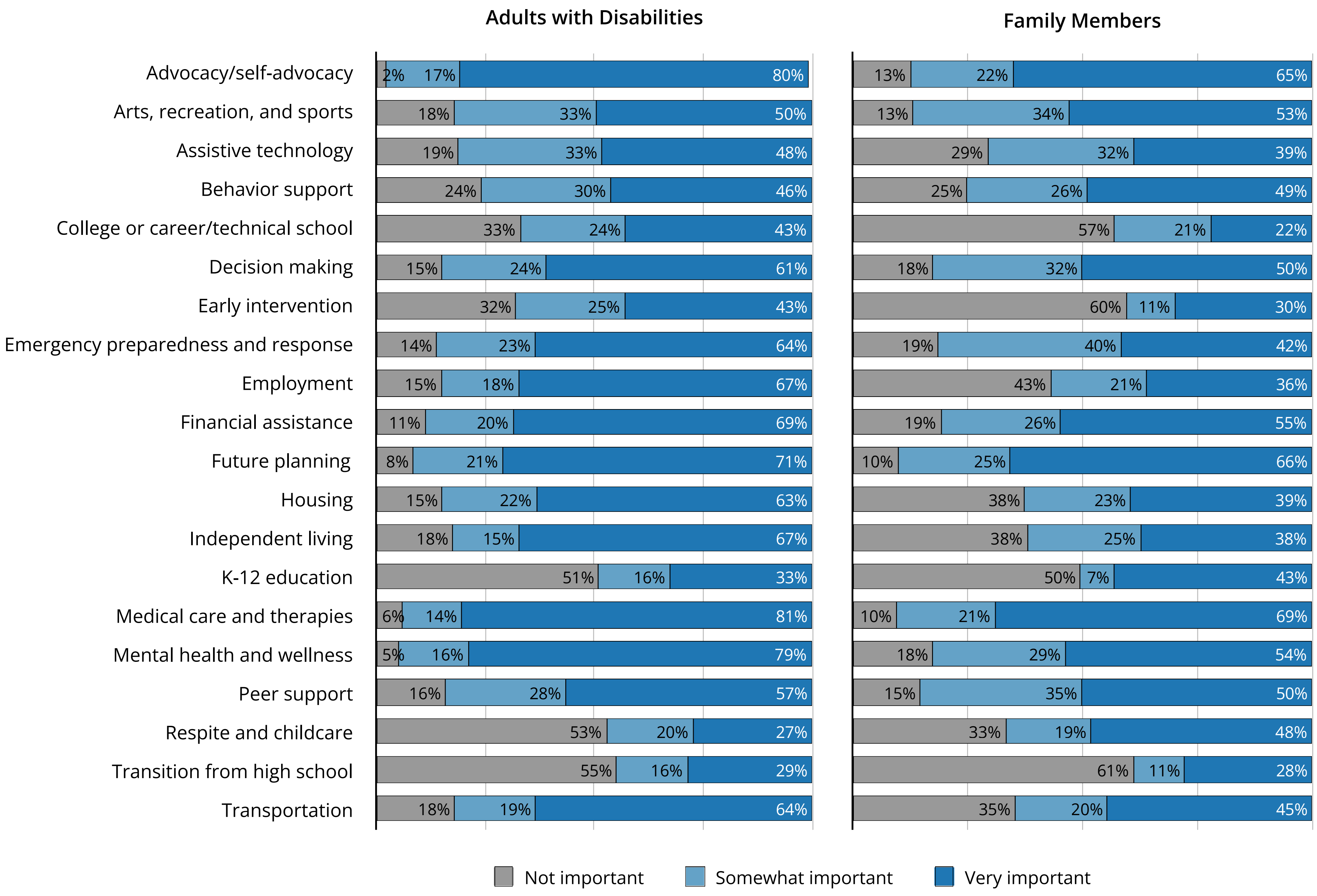


Table A5: Barriers to Finding Help – Theme Categories		
The help I need is hard to find because of…		
Theme	**Definition**	**Examples**
Lack of		
Direct service providers*	lack of support providers who are adequately trained, knowledgeable, and experienced working with individuals with disabilities	personal attendants, home health aides, low pay resulting in staffing issues, low provider rates, high turnover rates
Qualified providers*	lack of support providers who are adequately trained, knowledgeable, and experienced working with individuals with disabilities	knowledgeable medical providers, therapists, psychologists, psychiatrists, and educators
Resource and supports*	general reference to a lack of programs or services to assist individuals with disabilities in a variety of areas	
Rural resources	limited access to programs, services, and supports due to living in a rural area with few resources	
Finances	lack of sufficient financial support or resources to meet basic needs	high cost of medical appointments, inability to afford disability-related expenses
Transportation	lack of affordable, accessible, and reliable ways to get from one place to another	public transportation, rideshare programs, personal vehicles, availability of drivers
Funding	lack of financial support or investment from governments, organizations, or private entities to support services and programs	
Communication supports	lack of accommodations or challenges accessing resources to effectively communicate with others	interpreters, video remote interpreting, relay calls, supports for individuals who are nonverbal
Support for complex needs	limited access to programs specifically designed to support individuals with significant needs	programs to support complex health needs, significant behavior issues, extensive daily support needs
Disability awareness and advocacy	lack of education and advocacy efforts to promote awareness, acceptance, and the rights of individuals with disabilities	encountering ableism and social stigmas, misunderstanding of invisible disabilities, difficulty accessing ADA lawyers, lack of legal representation in appeals
Housing	lack of affordable, accessible, and safe places to live	
Accessible spaces	lack of buildings, public spaces, and events that are designed to be used and accessed by all people	design features include quiet spaces, seating in stores, ramps or low-rise steps
Adult resources	lack of programs, services, and activities specifically designed to support and accommodate adults with disabilities	adult or geriatric medical providers, adult ay programs, age-appropriate recreational activities
Mental health resources	lack of services and programs that provide support to individuals with mental health challenges, specifically tailor to those with disabilities	therapy providers, counseling centers or clinics, crisis intervention, and support groups
Support networks	lack of a group of individuals or organizations that provide emotional, practical, and social support, including both formal and informal social opportunities	peer support groups, community engagement initiatives, social clubs

Table A5: Barriers to Finding Help – Theme Categories		
The help I need is hard to find because of...		
Theme	**Definition**	**Examples**
Respite and childcare	lack of relief for family members or caregivers of individuals with disabilities through short-term care and support, either inside or outside of the home	
Employment opportunities and supports	lack of meaningful and well-supported employment opportunities	few job options, lack of accommodations, low pay, ineffective or hard-to-access supports and accommodations, fear of disclosing disability, workplace discrimination after disclosing
Family supports	lack of services and resources specifically designed to assist family members or unpaid caregivers	caregiver education and training, compensation for caregivers
Systemic issues		
Access to and managing benefits*	issues related to that obtaining or effectively managing financial assistance and healthcare programs offered by state or federal agencies	narrow eligibility requirements, differing program requirements, limited provider options, difficulties with application and renewal process
Access to supports	barriers that prevent individuals from receiving needed assistance including long waitlists, restrictive eligibility requirements, location	long waitlists, level of support needs, qualifying for support as a veteran, perception of neglect or unimportance within the system
Managing care	the physical, emotional, and logistical burden of coordinating care for an individual with disabilities	caregiver fatigue or burnout, juggling multiple responsibilities, managing care as loved one ages, lack of time for personal care due to caregiving demands
Navigating disability services	challenges understanding the complexities and polices of disability services and government programs	confusion over eligibility criteria, difficulty understanding scope of services, frequent changes in policy or program scope, lack of coordination between agencies
Special education services	challenges related to the implementation and enforcement of special education law and individualized student plans	schools not following IEPs, inconsistent behavior plan implementation, lack of accountability or enforcement mechanisms for IDEA compliance.
Disability law oversight	lack of adequate monitoring or enforcement of compliance with disability-related laws and the proper implementation of government-funded programs	ensuring Americans with Disabilities Act (ADA) compliance, and designating points of contact for concerns or complaints
Information access		
Lack of resource knowledge*	information about available supports and services is difficult to find, understand, or trust	not knowing where to start, being unsure who to ask, having trouble locating accurate, specific, or accessible information
Lack of centralized information	information and resources are not organized or coordinated among different organizations; information in one place contradicts information in another place	
Communication issues with providers	inability to access or a delay in accessing supports due to communication issues	returned calls, multiple transfers, dropped calls, responsiveness of staff, wait times

Note: Themes are grouped by category and ordered by frequency of mention within each. Top five most frequently mentioned themes across all categories are marked with a *.

Figure A2: Reported Support Types

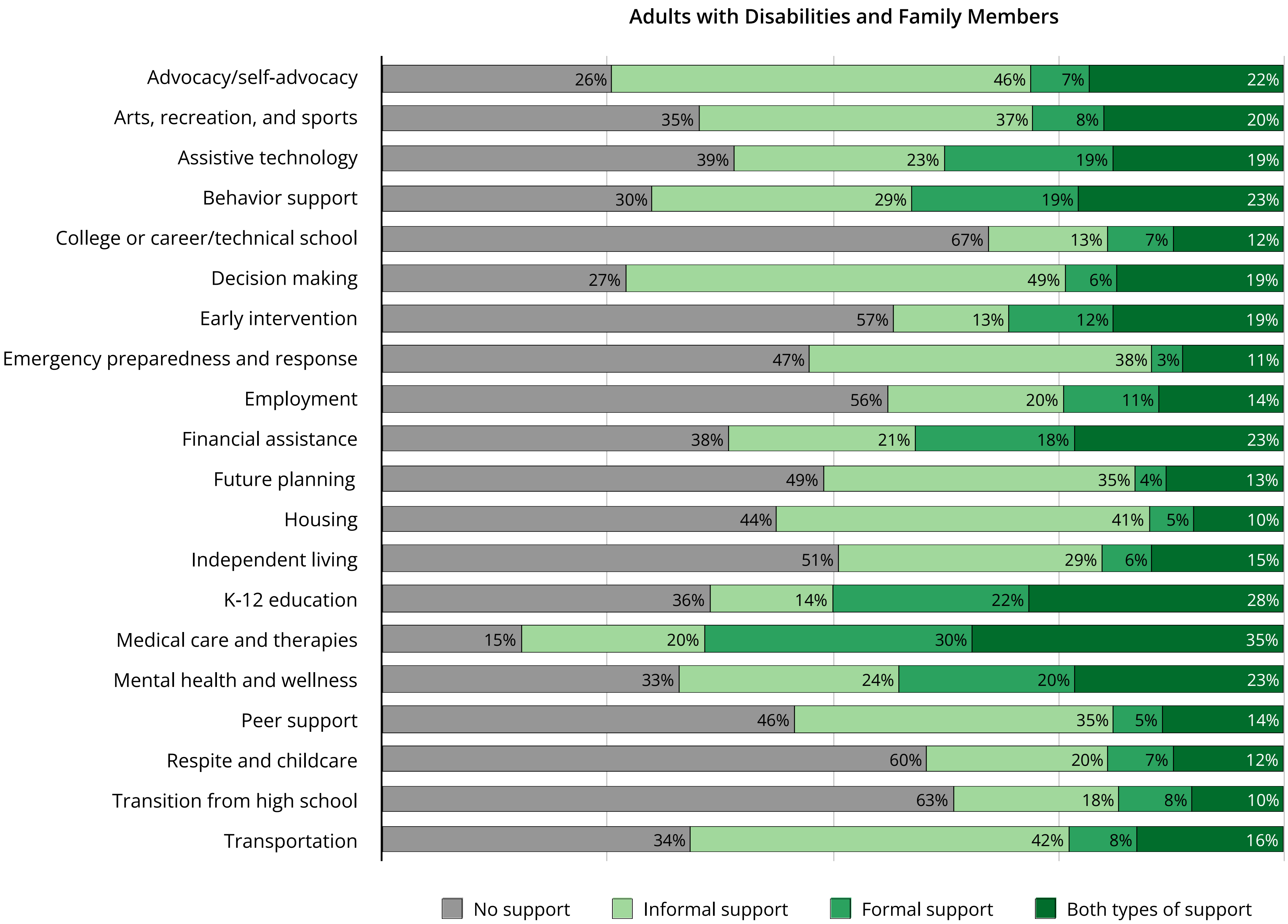


Figure A3: Reported Support Types by Role

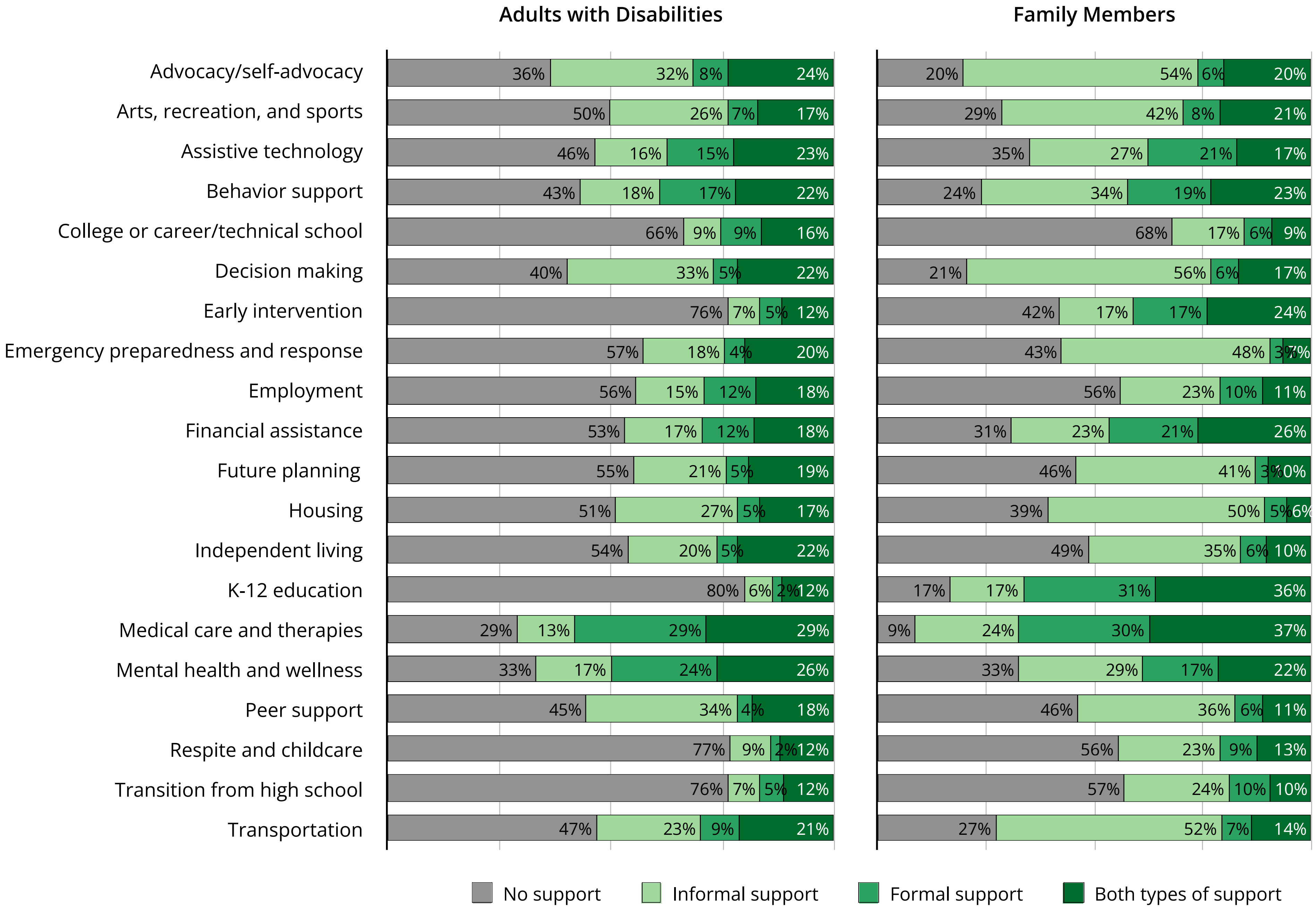
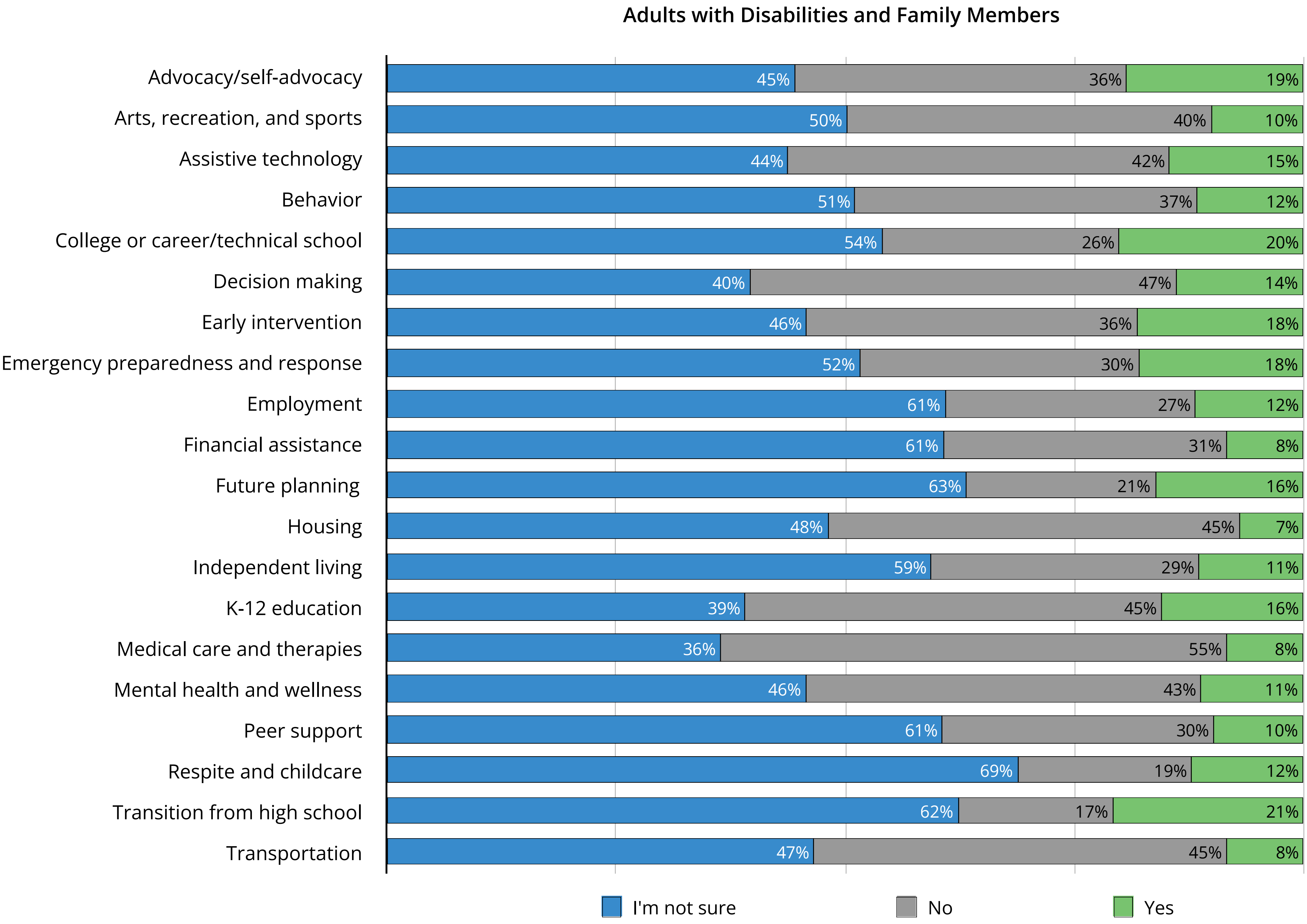


Figure A4: Reported Needs



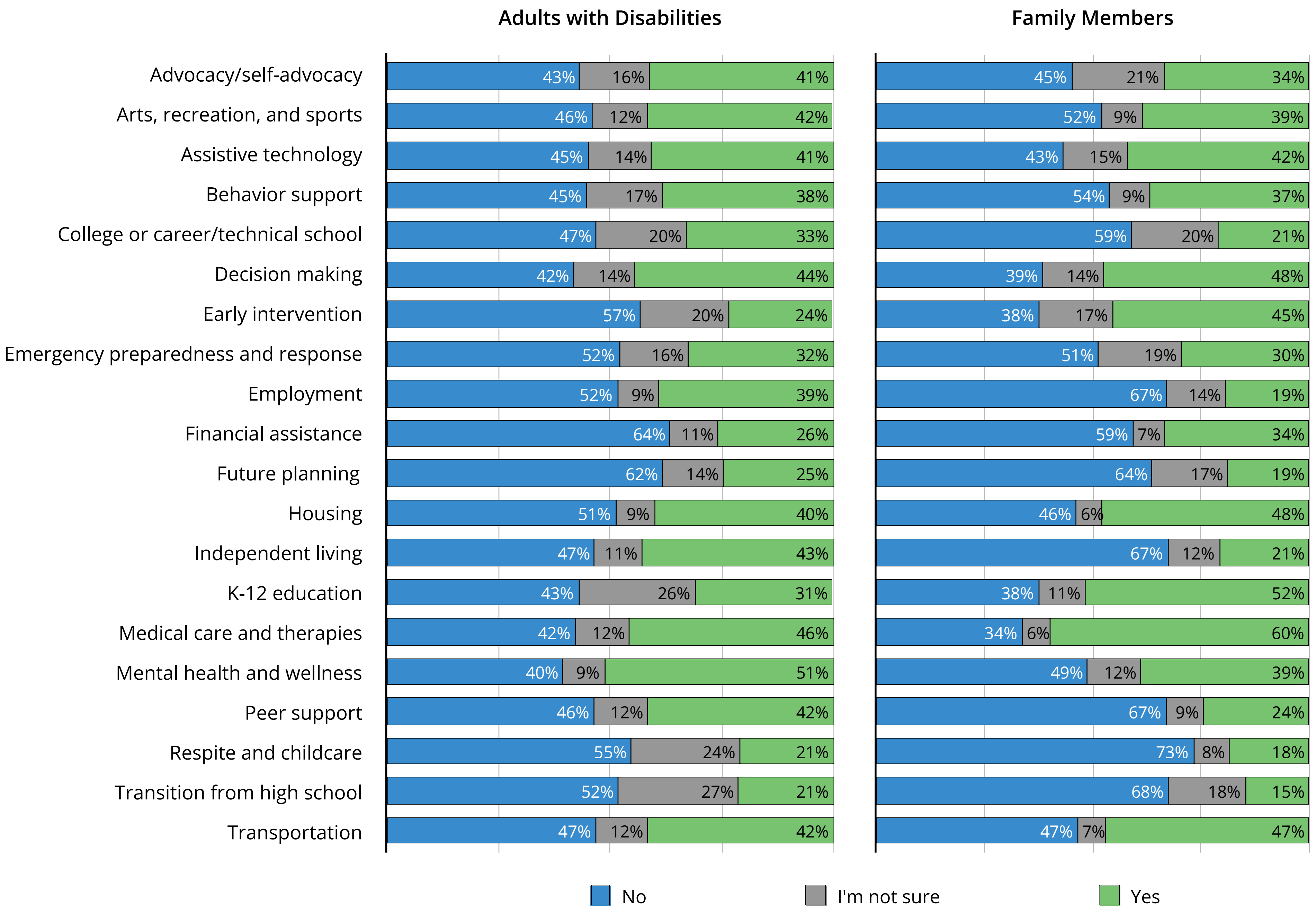


Figure A5: Reported Needs by Role

Figure A6: Barriers to Accessing Support

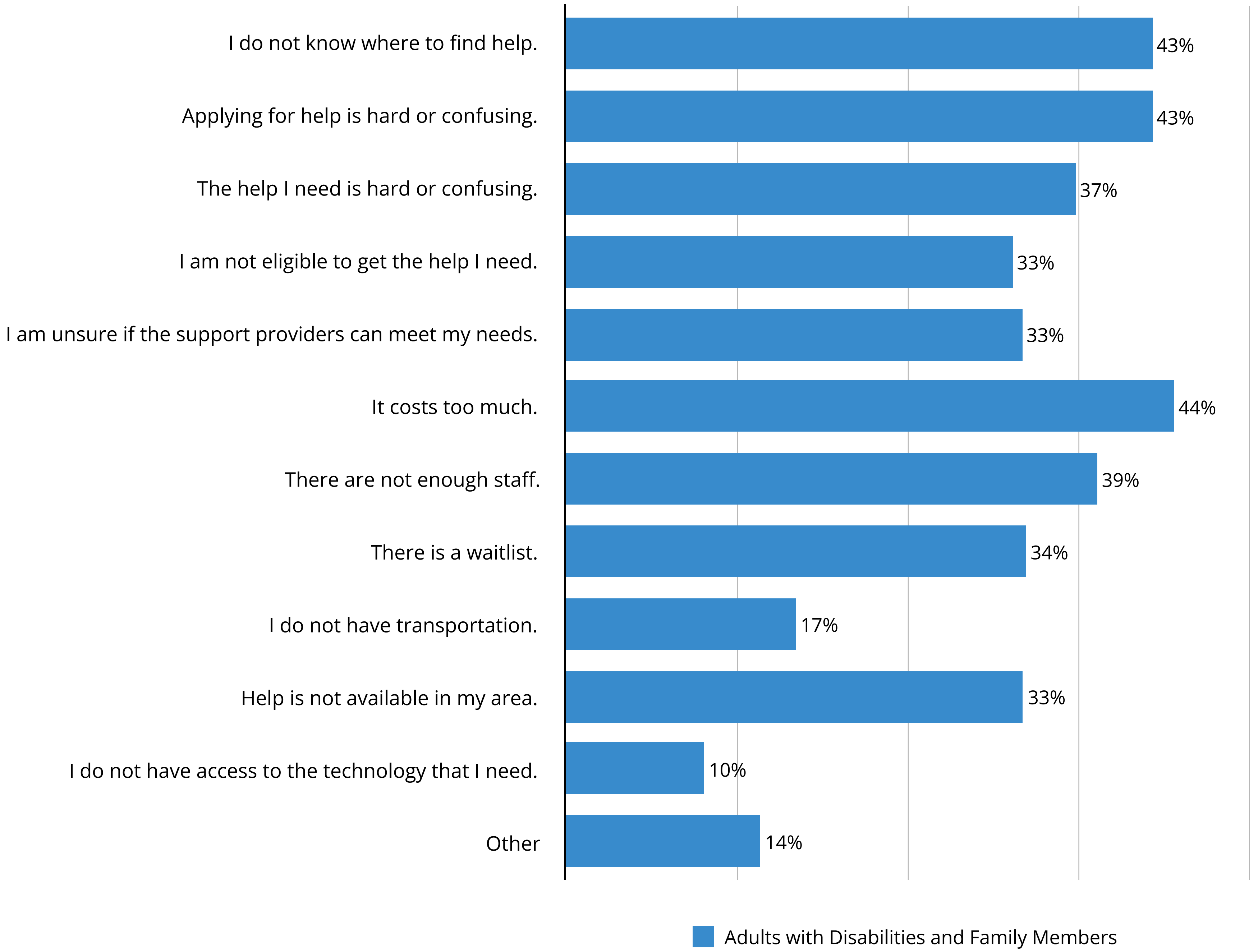


Figure A7: Barriers to Accessing Support by Role

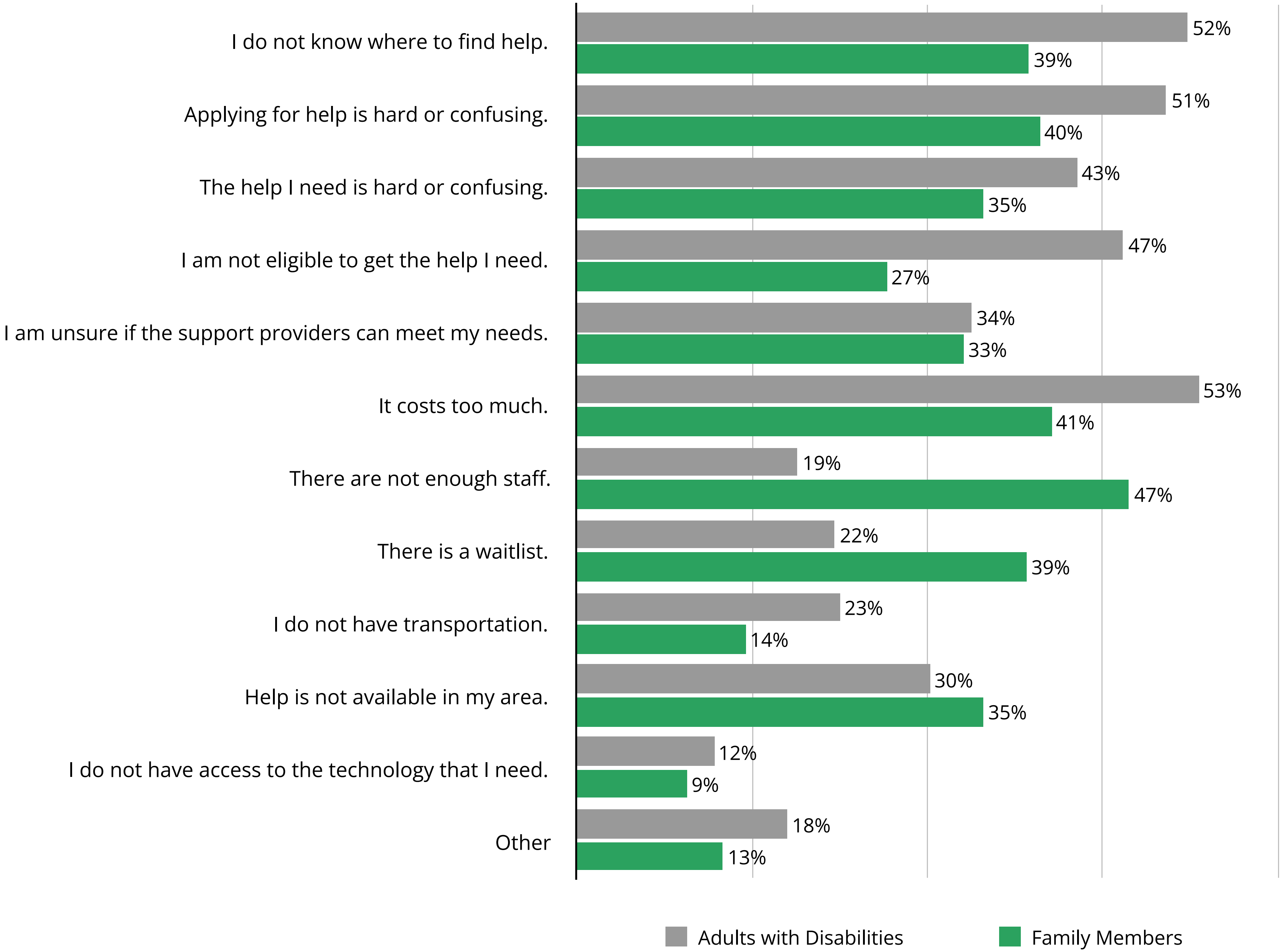


Table A6: Impactful State Efforts – Theme Categories		
Tennessee's most impactful efforts for people with disabilities center on...		
Theme	**Definition**	**Examples**
Accessible spaces and infrastructure	buildings, public spaces, and events that are designed to be used by and accessible to all individuals	sidewalk upgrades, wheelchair ramps, accessible parking, accessible bathrooms, adult changing tables, inclusive playgrounds
Advocacy and awareness	educating the public about disabilities, promoting respect and inclusion, and taking action to support the rights and interests of people with disabilities.	Disability Day on the Hill, Civic TN, REV Up, Partners in Policy Making, teaching the community about different disabilities, training for families, hosting conferences and events
Katie Beckett Program	a Medicaid waiver program that provides long-term services and supports to individuals with intellectual and developmental disabilities (I/DD), helping them live independently and pursue employment in community settings	
Medicaid	a state (TennCare) and federal program (Medicaid) that provides health insurance to low-income individuals, including children, pregnant women, people with disabilities, and older adults	access to healthcare and dental coverage
Benefits - Supplemental Security Income (SSI)	a federal program that provides monthly payments to people with low income and limited resources who are elderly or have a disability.	
Collaboration across organizations	building partnerships and relationships between government agencies, nonprofits, and service providers to improve supports for people with disabilities	increasing collaboration across agencies, unified work around staffing shortages, forming coalitions, coordinating services across local, state, and federal levels
Community engagement and recreation	programs and opportunities for individuals with disabilities to actively participate in community life and recreational activities through accessible and inclusive activities and events	Metro Parks disAbilities Program, Special Olympics, Younglife Capernaum, state parks, peer support programs
Disability awareness	educating the public about disabilities and promoting respect and inclusion	teaching the community about different disabilities, hosting conferences and events
Information access	ability to find and understand disability-related resources and services	plain language resources, increased outreach efforts, Tennessee Disability Pathfinder, Tennessee DeafBlind Project
Person centered planning	an individualized planning process that prioritizes the goal and preferences of the person with a disability in shaping their services	
Aging services	programs or supports for older adults (ages 60+) to help them live independently and with dignity	creation of Department of Disability and Aging (DDA), improved access to medical care, qualified support staff, focus on rights and protections
Early intervention services	services for infants and young children with developmental delays or disabilities and their families	Tennessee Early Intervention Services (TEIS), extending services to age 5
Employment services	programs, supports, and policies that help people with disabilities access, obtain, and maintain meaningful work	Vocational Rehabilitation, Empowerment and Community First CHOICES (ECF CHOICES), Medicaid Alternative Pathways (MAPS), Tennessee Integrated and Meaningful Employment Act, Project SEARCH, Employment First Taskforce, ADA enforcement, eliminating subminimum wage laws

Table A6: Impactful State Efforts – Theme Categories		
Tennessee's most impactful efforts for people with disabilities center on...		
Theme	**Definition**	**Examples**
Enabling technology	tools and devices that help individuals with disabilities live more independently at home, work, or in the community	Technology First, Tennessee Technology Access Program (TTAP)
Housing	access to of safe, affordable, accessible places to live	funding for group homes and family support model, integrated housing opportunities
Post-secondary education	opportunities, supports, and services in postsecondary education for students with disabilities	inclusive higher education programs, scholarship opportunities
Investments in services (funding)	general reference to increased funding to expand or improve services for people with disabilities	redistributing funds to better serve people, increasing pay for direct support providers and staff
K-12 education	supports and services within the K-12 public education system that help students with disabilities succeed in school and transition to adulthood	Tennessee Technical Assistance Network (TN-TAN), behavior training for educators, career and technical education (CTE), secondary transition supports
Mental health services	services and resources that support people with mental health conditions	Centerstone, TN START
Transportation	accessible, reliable, and affordable ways for people with disabilities to travel within their communities	paratransit, Access Ride, discounted rideshare programs
Unspecified state service	general reference to state-funded programs that offer direct support services (excluding financial aid) to individuals with disabilities	
Valuing lived experience	listening to and using feedback from people with disabilities to shape programs, services, and decisions	
Respite care	short-term relief for caregivers through temporary care services provided at home or in the community	grants to providers, Tennessee Respite Coalition

Figure A8: Perspectives on Community Inclusion by Role