

# Intellectual and Developmental Disabilities

## “You Don’t Know What You Don’t Know”: Parent Perspectives on Navigating Disability-Related Information and Resources

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<b>Abstract:</b>	We examined the priorities parents hold for their children with disabilities and the pathways through which parents access needed information and resources related to these valued areas. Our sample included 405 parents of children (ages 12 and under) who experienced a diversity of disabilities and varied support needs. Although each of the parents wanted their children to experience an array of formative experiences, the extent to which parents were familiar with local resources related to these important areas was uneven and often low. A constellation of barriers was said to stand in the way of connecting to the information and help they needed. When searching for disability-related information, parents often turned to a combination of sources, including professionals and technology.

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### **Abstract**

We examined the priorities parents hold for their children with disabilities and the pathways through which parents access needed information and resources related to these valued areas. Our sample included 405 parents of children (ages 12 and under) who experienced a diversity of disabilities and varied support needs. Although each of the parents wanted their children to experience an array of formative experiences, the extent to which parents were familiar with local resources related to these important areas was uneven and often low. A constellation of barriers was said to stand in the way of connecting to the information and help they needed. When searching for disability-related information, parents often turned to a combination of sources, including professionals and technology.

*Keywords:* families, expectations, children, developmental disabilities

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Parents care deeply about the well-being of their children. They want their daughters and sons to thrive in their education, health, relationships, personal growth, community connections, and other valued areas. The same is true for parents of children who have disabilities. Indeed, their aspirations for their children are likely to aim toward a similar array of experiences. For example, numerous studies highlight the importance parents place on ensuring their children can access meaningful experiences in school (e.g., Kauffman et al., 2022), at home (e.g., Bedell et al., 2011), and throughout the community (e.g., Blustein et al., 2016).

Unfortunately, many of the experiences that matter most to parents broadly remain elusive for children with disabilities (see Wehmeyer et al., 2017). When children have additional or ongoing support needs, accessing everyday experiences can be more challenging. This is particularly true when needed services and resources are limited, difficult to find, or unknown to parents. Educators and other professionals can play a critical role in ensuring parents are connected to information about all of the assistance and opportunities available to their child (Lawrence et al., 2023; Carter et al., 2022). In other words, connecting parents to the right information at the right time can help promote the thriving of their children with disabilities.

What, then, are the experiences that parents desire for their children with disabilities? And to what extent are parents familiar with local resources needed to pursue or support these experiences? These two questions provided the impetus for the present study. Previous research has explored the priorities of parents of children with disabilities in particular domains such as communication (e.g., Kwok et al., 2022; Stephenson & Dowrick, 2000), academics (e.g., Kurth et al., 2020; Starr & Foy, 2012), recreation (Schleien et al., 2014), and post-school outcomes (e.g., Blustein et al., 2016). However, less is known about the broader range of experiences

parents might value and the relative importance of each. For example, parents may weigh their expectations related to education, health, relationships, personal growth, community connections, and other valued areas differently. Knowing what matters most to parents could and should inform the work of educators, providers, and other disability professionals (Alsmari et al., 2018; McLeskey et al., 2017).

At the same time, parents typically need information and guidance to pursue valued experiences for their children with disabilities. This need may be elevated when their children have more extensive support needs (Peer & Hillman, 2014) or reside in communities with fewer resources (Thomas et al., 2007). However, the extent to which parents are familiar with resources related to their family priorities is less clear. Indeed, prior studies highlight the myriad difficulties parents face when trying to navigate the service system (e.g., Crais et al., 2020; Saaltink & Ouellette-Kuntz, 2014). For example, Resch et al. (2010) interviewed 40 parents of children with disabilities about the challenges they faced. Difficulties accessing information and services emerged as one of the primary barriers to parent well-being. Likewise, Alsem et al. (2017) interviewed parents of children with physical disabilities about their information seeking experiences and heard similar challenges. Additional research is needed to determine whether these challenges are common across all areas or accentuated in particular areas. Likewise, the specific nature of the barriers should be examined more closely.

In addition to understanding what parents know about available resources, it is also important to examine where they go for disability-related information. To whom or what do parents turn when they have questions about their child's needs? In their survey of 935 parents of children with autism in North Carolina, Gibson et al. (2017) found that parents accessed an array of information sources, including local (e.g., community organizations, professionals) and web-based (e.g., social media, national websites) sources. However, different sources were sought for

different needs. Through their surveys and interviews of Australian parents, Tracey et al. (2018) found that professionals, other parents, and the internet were frequent sources of information about their child's disability. Likewise, Grant et al. (2016) reported a heavy reliance on online resources in their interviews with Australian parents of children with autism.

The purpose of this study is to examine the priorities parents hold for their children with disabilities and the pathways by which they access needed information and resources in these key areas. We addressed the following research questions:

RQ1: What experiences do parents value for their children with disabilities?

RQ2: How familiar are parents with resources related to these valued experiences?

RQ3: How familiar are parents with resources related to key service needs?

RQ4: How do parents describe their experiences accessing needed information or resources?

RQ5: Which sources of disability information do parents consider most helpful?

## **Methods**

### **Participants**

Participants were 405 parents of children with disabilities ages 12 and under. To be included in the study, participants must have (a) been the parent, guardian, or conservator of someone with a disability; (b) been age 18 or older; and (c) lived in [state masked]. Our overarching project focused on parents whose children were all ages (e.g., infants, children, youth, adults). The current paper focuses on the subset of parents whose children were younger than 13, as the priorities and services for children often differ substantially from those of adolescents and adults. The majority (85.7%) of parent participants were female and nearly one quarter (23.0%) were non-white. Although their ages varied widely, 81.5% were between the ages of 30-49. The majority (83.0%) was either married or living with a partner. Nearly half (48.7%) had earned a bachelor's degree or higher. Their average number of children was 2.58

( $SD = 1.47$ ; range, 1-11) and the average number of children with disabilities was 1.26 ( $SD = 0.67$ ; range, 1-8). See Table 1 for parent demographic data.

Most of their children with disabilities were male (68.4%); the average age of their children was 7.48 ( $SD = 3.33$ ). Although many children were described as having more than one disability, the most frequently reported categories were autism spectrum disorder (49.9%), developmental delay (47.2%), and speech/language impairment (46.2%). When asked how much support their child needed to participate in daily living activities, 2.7% indicated no support, 12.8% said a little support, 26.9% said some support, 39.5% said a lot of support, and 18.0% said total support. Over half (58%) of children were reported to use speech (i.e., talking) as their primary method of communication. Most children were described as having good to excellent health (80.2%) and exhibiting challenging behavior less than monthly (53.5%). Most of their children (96.0%) lived at home with their parents. Table 2 displays child demographics.

### **Recruitment**

Recruitment took place over five months during the COVID-19 pandemic, beginning in December 2020. In the absence of a publicly available list of families impacted by disability, we adopted a multipronged approach to recruiting a large and diverse sample. We partnered with disability organizations, service providers, community programs, and school districts to extend study invitations to families throughout the state. This included 66 family-focused disability organizations (e.g., local Arc chapters, area Special Olympic programs, early intervention services, disability specific organizations, recreation programs) and 18 regional support groups for parents and family members of children with disabilities. We worked with each organization to identify promising ways of promoting the study, including crafting newsletter announcements, sending email blasts, distributing flyers, using paid and unpaid social media postings, and making presentations to key stakeholder groups. All recruitment materials included a link to the

project's website, which provided study information and a survey link.

We took several steps to encourage strong participation across the state. We allowed multiple completion options (i.e., online, in print, by phone). We offered the survey in both English and Spanish. We allowed surveys to be completed anonymously and at the convenience of the participant. Finally, we incentivized survey completion by randomly selecting 35 participants to receive a \$20 gift card and allowing participants to request free resources related to topics addressed in the survey (e.g., employment, independent living, relationships).

### **Measures**

We created a new survey to (a) explore the experiences parents felt were important for their child, (b) examine their familiarity with disability-related resources and services across multiple areas, (c) determine how they currently search for information and services, and (d) solicit recommendations for improving information and resource dissemination. We developed and piloted the survey in collaboration with a leadership team involving representatives of eight state agencies. Each of the sections addressed in the current paper are described below.

### ***Demographics***

In addition to personal demographics (e.g., sex, race/ethnicity, age band, marital status, highest level of education, community type), we asked parents how many children they have and how many of these children have disabilities. Parents then selected all of the disabilities experienced by their child, drawing from a fixed list that combined IDEA special education categories with additional disability groups identified by our state leadership team (see Table 2). Multiple options could be and often were selected for this question. We also asked about the age and sex of their child. Then we asked about level of support needed to do daily activities, primary communication method, physical health rating, and frequency of challenging behavior (see Table 2). Finally, we asked parents to indicate where their child presently lives.



### ***Valued Experiences***

We asked participants about the importance of everyday experiences for their children with disabilities. We presented them with a list of 13 experiences, including doing well in school, having friends, learning social and communication skills (see Table 3). These items were generated by reviewing the literature, through discussions with our state leadership team, and through feedback from stakeholder groups. We asked participants to rate the level of importance of experiences using a 4-point, Likert-type scale: 1 = *not important*, 2 = *a little important*, 3 = *somewhat important*, 4 = *very important*. We then asked them to respond to the following open-ended prompt: Are there any other important experiences not listed above?

### ***Resources Related to Valued Experiences***

We asked participants about their familiarity with community programs and services related to supporting everyday experiences from the previous survey section. We presented them with the same list of 13 childhood experiences and asked participants to indicate their familiarity with community programs or services that could help in each area using three response options: *No, I do not know who could help*; *Yes, I know who could help*; and *No help would be needed in this area*. Participants only addressed familiarity for areas they rated as important (e.g., a little important, somewhat important, very important) in the previous section.

### ***Resources Related to Service Needs***

We asked participants about their familiarity with community programs and services related to common service needs often utilized by individuals with disabilities and their families. We presented them with a list of 22 areas of assistance that might be needed by families of children with disabilities (e.g., assistive technology, behavior supports/services, respite care; see Figure 1). This list was also generated by reviewing the literature, through discussions with our state leadership team, and through feedback from stakeholder groups. We asked participants to

indicate their familiarity with community programs or services that could help in each area using three response options: *No, I do not know who could help*; *Yes, I know who could help*; and *No help would be needed in this area*.

### ***Experiences Accessing Information and Help***

We asked participants two questions about the ease of finding information needed to support their child with a disability and the ease of finding help for their child with a disability. Response options were: *very hard, somewhat hard, somewhat easy, and very easy*. We asked them to respond to the following open-ended prompt: What is your biggest question or need right now related to your child(ren)'s disability? We also asked them to indicate how often in the past year they needed information or help for their child with a disability, but did not know where to get it. Response options were: *never, 1-2 times, 3-5 times, 6-10 times, and more than 10 times*.

### ***Helpful Sources of Information***

We asked participants about the sources of information or resources that they found helpful. We presented them with a list of 16 commonly used sources of information (e.g., internet searches, books, research articles or journals, conferences or workshops, staff from state agencies or programs; Brock et al., 2014; Hodapp et al., 2018). Responses were provided on a 4-point, Likert-type scale: 1 = *not at all helpful*, 2 = *a little helpful*, 3 = *somewhat helpful*, 4 = *very helpful*. Next, we asked them to identify and rank the three sources of information they used most from the same list of 16 items (see Table 5). Finally, we included the following open-ended question: What (if anything) makes it hard to find the information you need?

### **Data Analysis**

All close-ended questions on the online survey were required, providing us with 405 submitted surveys with no missing data. We used SPSS software (SPSS 26; IBM Corporation, 2019) for all analyses. We did not include any respondents who finished some, but not all, of the

survey. For each research question, we summarized participants' responses by item using descriptive statistics.

We also undertook an exploratory analysis across all research questions to examine how three child and community characteristics might impact parent ratings. We used independent-samples *t* test and Pearson correlations to examine the association with disability type, support needs, and community type. For RQ1-RQ3, we examined parent ratings based on our three variables. First, we compared parent responses based on disability type: parents of children with autism versus parents of children with other disabilities (but not autism). We anticipated that parents of children with autism would have more familiarity with available resources, but more difficulty accessing needed information and resources. Second, we examined the strength of association between the child's level of support need using a Pearson correlation. We anticipated that parents of children with high support needs would have less familiarity with available resources and have more difficulty accessing needed information and resources. Last, we compared parent responses based on type of community: rural versus non-rural (i.e., suburban or urban) to determine whether there were distinct views or experiences associated with parents living in rural communities. We anticipated that parents of children living in rural areas would have less familiarity with available resources and have more difficulty accessing needed information and resources. We then examined the magnitude of any differences by calculating Cohen's *d*. For correlation coefficients and Cohen's *d*, we interpreted effect sizes using guidelines proposed by Cohen (1988): .20 was considered small, .50 moderate, and .80 large.

For RQ4, we used thematic coding to examine responses to open-ended responses. Three graduate students and one undergraduate student coded all open-ended responses. For both open-ended questions, we created a coding framework comprised of thematic codes and definitions, which served as a working document that coders added to throughout the process. Two students,

both serving as primary coders, used the coding framework to code all responses from each open-ended question independently. Upon completion, the two primary coders met with each other to compare their individual codes and agree upon one code per open-ended response. Following this, a second coder coded the same open-ended responses based solely on the updated coding framework. This coding process was guided by project staff.

## Findings

### What Experiences Do Parents Value for Their Children with Disabilities?

At least half of participants rated each of the 13 experiences as *somewhat* or *very important* (see Table 3). Overall, experiences with the highest ratings of importance were learning social and communication skills ( $M = 3.77$ ), having good mental health ( $M = 3.76$ ), and learning daily living skills ( $M = 3.73$ ). Experiences with the lowest importance ratings were attending summer camps/programs ( $M = 2.74$ ), attending community events ( $M = 2.85$ ), and participating in a faith community ( $M = 2.97$ ). The total number of areas each participant reported being *somewhat* or *very important* averaged 10.9 ( $SD = 2.45$ ). Other important experiences identified by participants in the open-ended section included: starting a family, experiencing a sense of belonging, having a job, and living independently.

Some differences were found based on disability type. The importance ratings of parents of children with autism were significantly higher on four items: learning social and communication skills,  $t(403) = 3.39, p = .001, d = .34$ ; having good mental health,  $t(403) = 2.17, p = .031, d = .22$ ; learning daily living skills,  $t(403) = 4.30, p < .001, d = .43$ ; and learning to make choices and decisions,  $t(403) = 3.09, p = .002, d = .31$ . Their ratings were significantly lower on one item: having friendships,  $t(403) = -1.98, p = .048, d = -.20$ . A small, negative correlation was found between level of support need and importance for one item: doing well in school ( $r = -.16, p = .001$ ). For parents living in rural communities, importance ratings were

significantly higher for five items: learning social and communication skills,  $t(403) = 4.05, p < .001, d = .38$ ; having good mental health,  $t(403) = 2.53, p < .001, d = .33$ ; learning daily living skills,  $t(403) = 2.53, p = .012, d = .30$ ; learning to make choices and decisions,  $t(403) = 2.17, p = .031, d = .25$ ; and being physically healthy,  $t(403) = 3.29, p = .001, d = .32$ .

### **How Familiar Are Parents with Resources Related to These Valued Experiences?**

At least half of participants indicated they knew of programs or services in their community that could help their children with disabilities in 8 of 13 experiences (see Figure 1). Overall, they were most familiar with resources related to doing well in school (68.6%), being physically healthy (67.7%), and learning social and communication skills (66.0%). They were least familiar with resources focused on attending summer camps/programs (46.6%), having friendships (45.1%), and participating in recreational activities (44.1%).

The average number of experiences for which parents indicated they needed help was 11.2 ( $SD = 2.77$ ). The total number of experiences for which parents needed help was significantly higher for parents of children with autism,  $t(403) = 2.74, p = .006, d = .27$ . No correlation was found between support level and total number of experiences that parents need help. No significant difference was found for parents living in rural communities.

The average number of experiences for which parents did not know who could help was 4.4 ( $SD = 3.98$ ). The total number of experiences for which parents do not know who can help was significantly higher for parents of children with autism,  $t(403) = 3.73, p < .001, d = .37$ . No correlation was found between support level and total number of experiences that parents do not know who can. No significant difference was found for parents living in rural communities.

### **How Familiar Are Parents with Resources Related to Key Service Needs?**

At least half of participants indicated they knew of programs or services in their community that could help their children with disabilities in nine of 22 areas of service need (see

Figure 1). Overall, they were most familiar with resources related to interpretation or speech therapy (74.6%), occupational therapy (72.3%) and physical therapy (67.2%). They were least familiar with resources focused on benefits counseling (60.0%), financial assistance (54.8%), and parent or sibling support groups (52.3%).

The average number of experiences for which parents needed help was 17.3 ( $SD = 5.04$ ). No significant difference was found based on disability type. A small, positive correlation was found between support level and total number of experiences that parents need help ( $r = 0.31, p < .001$ ). No significant difference was found for parents living in rural communities.

The average number of experiences for which parents did not know who can help was 7.5 ( $SD = 5.58$ ). No significant differences were found based on disability type, level of support, and community type.

### **How Do Parents Describe Their Experiences Accessing Needing Information or Resources?**

When asked how easy it is to find the information needed to support their children with disabilities, 20.2% said *very hard*, 53.6% said *somewhat hard*, 21.0% said *somewhat easy*, and 5.2% said *very easy*. When asked how easy it is to find the help needed to support their children with disabilities, 32.8% said *very hard*, 45.2% said *somewhat hard*, 17.5% said *somewhat easy*, and 4.4% said *very easy*. We asked participants to share their biggest question or need right now related to their children's disabilities, the top three themes identified were finding services, financial assistance, and medical or healthcare (see Table 4). When asked how often they needed information or help for their children with disabilities, but did not know where to get it, 10.1% said *never*, 34.6% said *1-2 times*, 32.1% said *3-5 times*, 10.6% said *6-10 times*, and 12.6% said *more than 10 times*.

### **Which Sources of Information Do Parents Consider Most Helpful?**

For 8 of the 16 sources of information we listed, at least half of participants considered

each to be *somewhat* or *very helpful* (see Table 5). They rated the following sources as most helpful: doctors, therapists, or other medical professionals ( $M = 3.13$ ); internet searches ( $M = 2.95$ ); and social media ( $M = 2.76$ ). The least helpful resources included podcasts ( $M = 1.87$ ), blogs ( $M = 2.09$ ), and my own family members ( $M = 2.16$ ). Other helpful sources of information identified included: community events, disability ministries, autism centers, and advocacy groups. The items most often ranked among the top three sources were internet searches (33.6%), social media (17.3%), and doctors, therapists, or other medical professionals (12.8%).

We also asked participants to identify what made it hard for them to find needed information (see Table 6). The top challenges identified by parents include the search process, technology skills, and lack of resources. As one parent lamented, “You don’t know what you don’t know.” Parents described difficulties related to finding information because of “not knowing where to start” and “not knowing what we should be looking for.” Even if parents knew where to search, sometimes accessing information online was a barrier. One participant wrote, “Research articles or publications are very difficult to find through general internet searches. If we had access to quality references to search for, medical or other published work, it would be incredible.” Others described difficulties related to finding information specific to their child’s needs. One participant expressed her frustration, “Both my children don’t fit into typical molds” Another participant shared, “disabilities are so personal that broad information is not always applicable” Similarly, another participant wrote “Every individual’s needs are so unique; information is usually generic.”

Participants also identified “navigating websites” and “no access to internet” as a barrier to finding information. One participant explained, “I don’t know how to use the internet.” Another parent explained, “It is hard to know which internet sources are trustworthy.” Others shared frustrations with how websites and information were organized, saying “Information is

not centralized in one place” and described the process as “too confusing.” Another prevalent theme was lack of resources. One participant described her difficulties explaining, “I can’t find anything in my area.” One mother expressed frustration explaining, “Everyone refers us to somewhere else. It is an endless circle that leads nowhere.” Another explained, “I spend hours and hours on the phone trying to find help. No one has the answer or correct information.” Another parent simply wrote the word “exhaustion” to capture their hardships. Some had difficulty identifying just one reason why finding needed information is hard. One parent responded, “The list is too long to write. The anxiety, stress, and frustration is taking a toll on myself and his mother [when] finding the best care for him.”

### **Discussion**

Most parents want their daughters and sons with disabilities to enjoy the same formative childhood experiences as any other young person. This pursuit can be enhanced when parents have access to information about relevant community programs and services that can help in these areas (Hall et al., 2016; Saaltink & Ouellette-Kuntz, 2014). We explored an array of experiences that might be valued by parents and examined issues related to accessing needed information and resources. Our findings provide new insights into the experiences of families and the need for more robust dissemination efforts by schools and disability organizations.

First, we found that most parents highly valued a variety of school, home, and community experiences for their children with disabilities. This included having friendships, participating in recreational activities, learning daily living skills, being part of their local community, and doing well in school, among others. Indeed, very few parents considered any of the 13 experiences we presented to have no importance at all (range, 0.5-12.1%). Accessing this breadth of childhood experiences can contribute to the overall well-being of children with disabilities (Renwick et al., 2003). This portrait of priorities suggests there may be more



similarities than differences in what parents want for their children with and without disabilities. It also affirms the importance of adopting a holistic approach to coordinated service delivery. Although schools, community programs, and healthcare providers each have their distinct service foci, their collective work should aim toward advancing what matters most for the children and families whom they serve (Alsmari et al., 2018; McLeskey et al., 2017).

Second, parents varied widely in their familiarity with programs or services that could help their children in the areas they said they valued. Across areas, the percentage of parents who *did not know* who could help them ranged from 21% to 47%; the average was nearly 5 of 13 areas. Familiarity with resources related to attending summer camps/programs, having friendships, and participating in recreational activities was the most limited. A similar pattern was evident when considering key service needs. Here, the percentage of parents who *did not know* who could help them ranged from 13% to 60% areas; the average was nearly 8 of 22 areas. Here, familiarity with resources related to family supports and fiscal issues tended to be most limited. Overall, these findings suggest that some parents know more about where to turn for help than do others. For example, parents of children with autism identified more experiences for which help was elusive than did parents of children with other disabilities. Educators, providers, and other professionals should identify new avenues through which needed information can be shared with families in timely and accessible ways.

Third, the quest for guidance and assistance remains complicated for a large proportion of parents. Specifically, three quarters of parents said it was somewhat or very hard to find the information or the help they needed to support their children with disabilities. Moreover, 90% of parents noted that there were times when they needed information or help, but they did not know where to get it. Such enduring challenges have also been raised elsewhere in the literature (e.g., Gilson et al., 2017; Resch et al., 2010). Parents in our study described having a host of questions

related to finding services, accessing financial assistance, navigating medical and health care issues, and securing respite services. Likewise, they detailed multiple factors that converge to make disability-related information hard to find, including difficulties related to technology, time, misinformation, and available resources. Taken together, these findings suggest that resolving information access barriers is likely to require multi-faceted and coordinated solutions.

Fourth, parents shared their preferred sources for disability-related information. Views regarding who or what was most helpful varied across both information sources and parents. Overall, large proportions of parents considered (a) doctors, therapists, and other medical professionals; (b) internet searches; and (c) social media to be the most helpful (and their top) sources for information. The reliance on healthcare providers is not altogether surprising given their prominence in the lives of many children and families (Wehmeyer et al., 2017). Moreover, questions about medical and healthcare needs were among the areas in which parents had their biggest questions. Likewise, parents' reliance on internet searches and social media for disability information was expected given their ubiquity. Yet, parents also named difficulties navigating technology as another key challenge when trying to find what they need. This reliance on technological pathways to accessing information is also shared by special educators (Lawrence et al., 2023) and disability service providers (Carter et al., 2022). However, parents also affirmed the helpfulness of interpersonal pathways to accessing information, through other families, teachers, and friends.

### **Implications for Practice**

Parents need good information and relevant services to help their children with disabilities thrive. Findings from this study have implications for how local and state entities approach the task of equipping families in these areas. First, professionals should strive to understand the breadth of experiences parents are seeking for their sons and daughters with

disabilities. Knowing what matters most to families can help guide schools and communities in developing the right resources and ensuring local families are aware of them. In other words, parents can provide an important source of social validation when determining critical service and support gaps to fill. Second, professionals should reflect on the specific factors that keep parents in their community from accessing needed information and resources. This study suggests a number of possibilities, including the paucity of local services, the complexity of presented information, the scattered nature of resources, the challenges of using technology, the nature of their child's needs, or the uncertainty of where to start. However, the particularities of each city, county, and state suggest that local reflection may be especially important. In other words, educators and providers should ask about the experiences of and challenges faced by the families they currently serve as they work toward better solutions.

Third, this reflection—and response—should be undertaken as a collaborative endeavor. The experiences parents value and the service needs they report cut across multiple professional disciplines and life domains. Bringing together educators, state agencies, community programs, health care providers, and other service providers can ensure that a more coordinated and comprehensive approach to information dissemination is achieved. This could involve developing a local or state task force focused on new ways of creating, compiling, and sharing resources with area families (Hodapp et al., 2018). Fourth, there is unlikely to be a “one-size-fits all” approach to information dissemination that works for all families. Indeed, the priorities and preferences reflected in this and other studies (e.g., Gibson et al., 2017; Gilson et al., 2017) suggest that parents want and need an array of options. Disability professionals and educators need to understand and consider the preferences of parents when designing their dissemination and outreach efforts. Fifth, professionals are—and will continue to be—prominent and valued source of information for parents of children with disabilities. Thus, it is important that

educators, providers, and other professionals are themselves familiar with community resources that address the pressing needs and questions of families. Strong professional development opportunities should be made available to ensure educators and healthcare workers know of community resources and supports (Crais et al., 2020).

### **Implications for Policy**

Our findings suggest key directions for policy. First, this study demonstrates the need for robust and effective statewide information systems. State and federal agencies are usually charged with having an information and referral component. These requirements should be accompanied by clearer expectations and outcomes. With the strong reliance on internet searches and social media reported by parents, agencies should be expected to keep their internet websites and other resources accessible and up to date. Second, the existing disability systems already in place in every state must help offer better coordination and dissemination of information to families. For example, every state has a Developmental Disabilities Network comprised of Councils on Developmental Disabilities, University Centers for Excellence in Developmental Disabilities, and Protection and Advocacy agencies (Developmental Disabilities Assistance and Bill of Rights Act of 2000). These entities can often be a source of information for families. Another potential partner includes the nearly 100 Parent Training and Information Centers and Community Parent Resource Centers across the country. Third, training programs—especially those for doctors, therapists, and other medical professionals—should address the importance of sharing information and resources with families including a member with a disability. Many of the agencies listed above could partner for training so that health care clinicians and their administrative staffs can provide linkages to up-to-date information in the community.

### **Limitations and Future Research**

Several limitations to this study suggest areas for future research. First, every state differs

somewhat in its approach to service delivery, policies, and available resources. Because our sample was drawn from a single state, we cannot speak to whether the experiences parents encountered here will align or diverge from what parents experience elsewhere. Replicating this study in other states would provide important insights into whether the complexities associated with information access are evident elsewhere. Second, although the racial/ethnic composition of our sample reflected current state demographics, their educational level was considerably higher (48.7% had at least a bachelor's degree compared to 30.3% of the general population). Even amidst these higher levels of education, however, most parents still experienced substantial barriers to information access. The role of educational level should be examined more closely in future studies. Third, the portrait of parents also varies widely across the country. The breadth of families residing in the United States cannot be captured within a single state. More research is needed to understand whether and how the values and experiences of families in this area differ in light of cultural, linguistic, economic, and other forms of diversity. Fourth, our findings describe parent perspectives at a single point in time. This study was designed, in part, to inform the next iteration the state's information and referral services. As statewide services are refined in response, it will be important to track whether parents actually find it easier to locate the information and help they need. Although multiple studies have described the challenges families face, the field also needs studies examining the effectiveness of proposed solutions.

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## NAVIGATING INFORMATION

1

**Table 1***Demographics of Parents*

Variable	<i>n</i>	%
Sex		
Female	347	85.7
Male	58	14.3
Age		
Under 20	0	0.0
20-29	31	7.5
30-39	171	42.2
40-49	159	39.3
50-59	33	8.1
60-69	11	2.7
70 or older	0	0.0
Race/ethnicity <sup>a</sup>		
American Indian and Alaska Native	16	4.0
Asian	4	1.0
Black or African American	36	8.7
Hispanic/Latino	37	9.0
Native Hawaiian & Other Pacific Islander	2	0.5
White	318	77.0
Marital status		
Single	29	7.2
Married/living with partner	336	83.0
Separated/divorced	32	7.9
Widowed	3	0.7
Prefer not to answer	5	1.2
Highest level of education		
High school or less	16	4.0
High school diploma or GED	37	9.1
Some college	88	21.7
Certification program	23	5.7
Associate's (two-year degree)	40	9.9
Bachelor's (four-year degree)	96	23.7
Master's degree	80	19.8
Doctoral degree	21	5.2
Prefer not to answer	4	1.0
Community type		
Rural	134	34.5
Suburban	169	43.6
Urban	85	21.9
Prefer not to answer	17	4.6

<sup>a</sup>More than one option could be selected; total percentages exceed 100%

**Table 2**  
*Demographics of Children with Disabilities*

Variable	<i>n</i>	%
Sex		
Female	128	31.6
Male	277	68.4
Disability <sup>a</sup>		
Autism spectrum disorder	202	49.9
Deaf-blindness	22	5.4
Deafness	42	10.4
Developmental delay	191	47.2
Hearing impairment	54	13.3
Learning disability	148	36.5
Intellectual disability	122	30.1
Mental illness, mental health disorder, or EBD	66	16.3
Other health impairment or ADD/ADHD	108	26.7
Physical disability	91	22.5
Speech/language impairment	187	46.2
Traumatic brain injury	28	6.9
Visual impairment	48	11.9
Substance abuse disorder	3	0.7
Other	54	13.3
Support needed to do daily living activities		
No support	11	2.7
A little support	52	12.8
Some support	109	26.9
A lot of support	160	39.5
Total support	73	18.0
Primary method of communication		
Talking	235	58.0
Using pictures or a communication device	18	4.4
Sign language or other signs	39	9.6
Gestures, facial expression, sound/vocalizations, or other body movements	93	23.0
My child does not intentionally communicate with others	20	4.9
Overall physical health rating		
Poor	17	4.2
Fair	63	15.6
Good	146	36.0
Very good	127	31.4
Excellent	52	12.8
Frequency of challenging behavior		
Never	119	29.4
Yearly	39	9.6
Monthly	59	14.6
Weekly	79	19.5
Daily	109	26.9

<sup>a</sup>More than one option could be selected; total percentages can exceed 100%.

**Table 3**  
*Parents Importance Rating of Valued Experiences*

Item	Percentage responding				<i>M (SD)</i>	Factors		
	Not at all important	A little important	Somewhat important	Very important		ASD <sup>a</sup>	Level of support	Rural <sup>a</sup>
Learning social and communication skills	0.5	4.4	13.1	82.0	3.77 (0.55)	.34*	.04	.38*
Having good mental health	1.2	3.5	13.3	82.0	3.76 (0.57)	.22*	.02	.33*
Learning daily living skills	2.0	4.4	11.9	81.7	3.73 (0.64)	.43*	.02	.30*
Learning to make choices and decisions	1.7	5.9	13.8	78.5	3.69 (0.66)	.31*	-.04	.25*
Being physically healthy	0.5	6.9	16.0	76.5	3.69 (0.62)	.00	.07	.32*
Experiencing personal growth	1.0	7.4	22.7	68.9	3.60 (0.67)	.16	.00	.18
Having friendships	1.0	8.4	30.9	59.8	3.49 (0.69)	-.20*	-.09	-.11
Doing well in school	4.9	9.9	25.9	59.3	3.40 (0.86)	.08	-.16**	.07
Being part of their local community	2.7	21.5	33.3	42.5	3.16 (0.85)	.00	.08	-.02
Participating in recreational activities	3.7	16.0	42.5	37.8	3.14 (0.82)	.00	-.02	-.06
Participating in a faith community	12.1	20.0	26.7	41.2	2.97 (1.05)	-.12	.07	.00
Attending community events	5.9	28.1	40.7	25.2	2.85 (0.87)	-.10	.01	-.08
Attending summer camps/programs	12.1	27.4	34.6	25.9	2.74 (0.98)	-.04	.01	-.19

<sup>a</sup>Cohen's *d*.

\**p* < .05. \*\**p* < .01.

**Table 4**  
*Biggest Question or Needs Related to Their Children’s Disabilities`*

Code <sup>a</sup>	Definition
Finding services	Finding service providers to meet their child’s needs; accessing services (e.g., wait lists, distance to provider); navigating the service system)
Financial assistance	Support to pay for therapies and medical care; understanding and utilizing government benefits
Medical or healthcare	Information or medical needs related to child’s disability; finding and accessing healthcare providers and medical equipment
Respite care	Short-term caregivers to provide a break for primary caregivers
Behavior	Behavior support for parents and/or strategies for managing their child’s challenging behavior; connecting with behavior services (e.g., behavior therapies, applied behavior analysis services)
School-based services	Special education services or academic supports (e.g., skill development, curriculum modifications, accommodations, homeschool support)
Planning for future	Concerns about future and what will happen when parent or caregiver is no longer able to provide support
Coronavirus pandemic	Concerns about regression (academically and socially) due to changes in services due to pandemic; help or support related to virtual learning
Social skills	Social skills training, support groups, and/or increasing social interaction
Communication	Support related to child’s communication skills and needs
Mental healthcare	Mental health services and resources
Community access	Finding inclusive community events or programs (e.g., recreational activities, place of worship, summer camps)
Adaptive equipment	Obtaining adaptive equipment and assistive technology
Housing	Independent or supported living opportunities and programs
Employment	Employment opportunities and navigating employment services
Conservatorship	Information and support regarding conservatorship
Where to start	Unsure where to begin when looking for resources, services, or information
Eligibility	Availability and timing of diagnostic and evaluative testing; eligibility for services; accessing services

<sup>a</sup>Listed in descending order based on total number of responses related to this code.

**Table 5***Parents Ratings of the Helpfulness of Various Sources of Information*

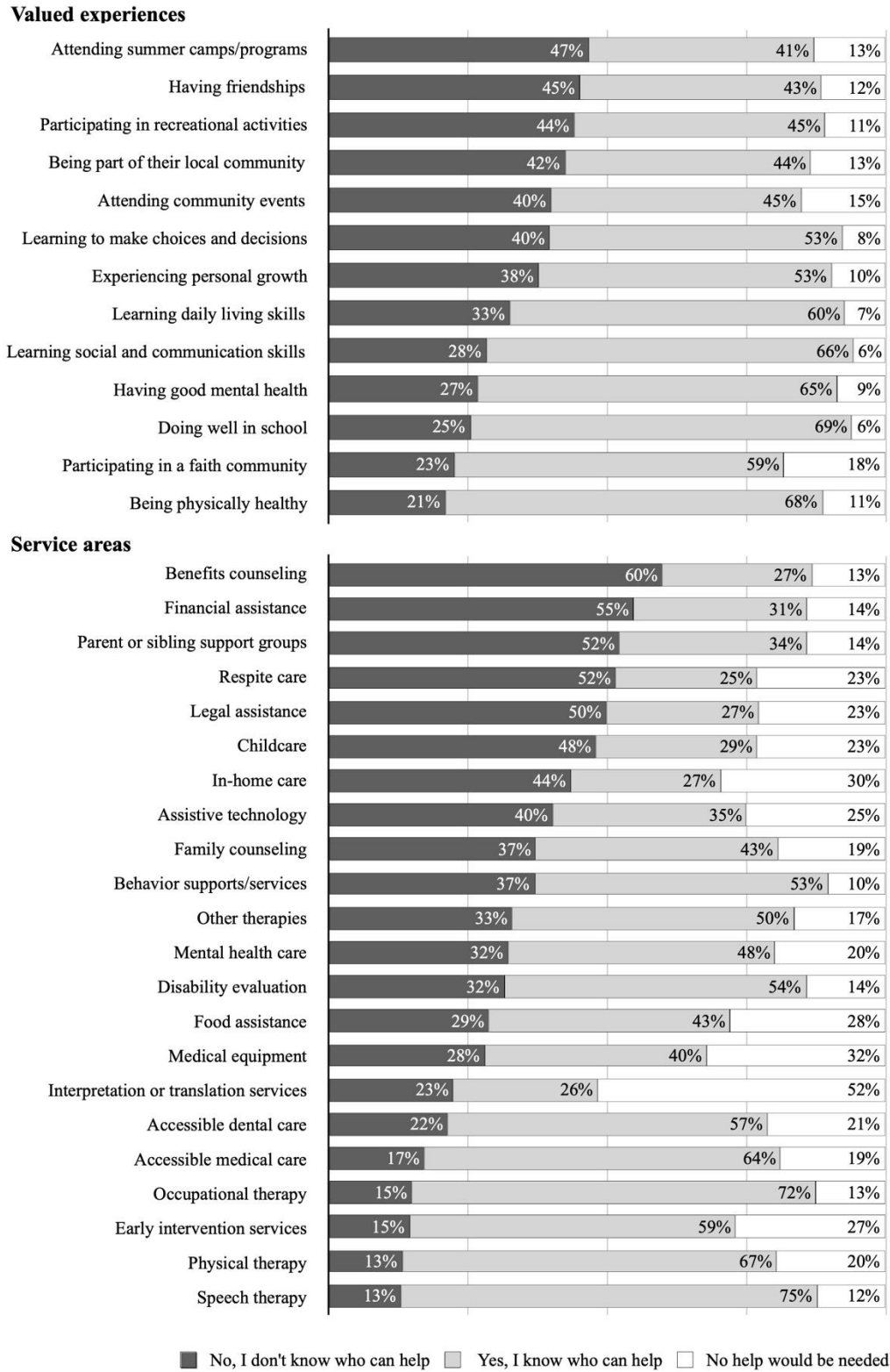
Item	Percentage responding				<i>M (SD)</i>
	Not at all helpful	A little helpful	Somewhat helpful	Very helpful	
Doctors, therapists, or other medical professionals	3.7	20.2	35.1	41.0	3.13 (0.86)
Internet searches	3.2	26.9	41.7	28.1	2.95 (0.82)
Social media (like Facebook, Twitter, or Instagram)	10.9	25.4	40.2	23.5	2.76 (0.93)
Other families with members with disabilities	20.0	21.5	29.4	29.1	2.68 (1.10)
Research articles or journals	13.8	27.2	36.3	22.7	2.68 (0.98)
Teachers or other school staff	18.8	24.7	30.9	25.7	2.63 (1.06)
Friends	18.8	26.9	29.1	25.2	2.61 (1.06)
Books	20.0	29.9	34.8	15.3	2.45 (0.98)
Conferences or workshops	26.7	25.4	25.7	22.2	2.43 (1.11)
Online videos	22.5	31.9	29.9	15.8	2.39 (1.00)
Staff from state agencies or programs	27.7	25.9	27.7	18.8	2.38 (1.08)
Local/state disability organizations	30.1	26.2	24.7	19.0	2.33 (1.10)
National disability organizations	35.6	28.9	19.3	16.3	2.16 (1.09)
My own family members	36.5	26.2	22.2	15.1	2.16 (1.08)
Blogs	34.8	33.3	20.0	11.9	2.09 (1.01)
Podcasts	46.4	28.1	17.0	8.4	1.87 (0.98)

**Table 6**

*What Makes Information Hard to Find for Parents*

<b>Code<sup>a</sup></b>	<b>Definition</b>
Search process	Unable to access or connect with needed information or resource during search process (e.g., keyword searches do not yield desired results, information found is not specific or detailed enough)
Technology skills	Difficulty using computers and navigating websites
Lack of resources	Lack of or limited availability of resources in a particular area
Time commitment	Not enough time to research and find information
Misinformation	Incorrect or out-of-date information; difficult to discern whether information is reliable
Unsure where to start	Unsure where look for information or what questions to ask
Trouble understanding	Difficulty understanding information or resources due to terminology use
Connecting with providers	Problems connecting with service providers (e.g., difficulty finding contact information, receiving a call back)
Lack of rural resources	Lack of or limited resources in rural locations
Financial issue	Limited financial assistance or funding for disability-related needs and resources; do not qualify for financial assistance
Lack of organization	Information is not streamlined or consistent across different state agency or organization websites; information is not centralized in one location
Feeling overwhelmed	Overwhelmed by the amount of information available and number of sources
Less prevalent disability	Difficulty finding information due to lack of research or information on a rare disability
Coronavirus pandemic	Stress of pandemic and changes in daily life impact time and mental capacity to research or find information

<sup>a</sup>Descending order by number of responses



**Figure 1.** Parents Familiarity with Resources to Support Valued Experiences and Key Service Needs