Inclusion

“Too Many Brick Walls”: Perspectives on Accessing Disability Information and Resources Among Service Providers

--Manuscript Draft--

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Abstract:	Disability service providers are often critical sources of guidance for individuals with intellectual and developmental disabilities (IDD) and their families. This study examined the extent to which these professionals were familiar with community resources that could help support the inclusion of individuals with IDD in valued experiences and help meet pressing service needs for families. We surveyed 294 service providers about their familiarity with disability-related resources, their experiences trying to access needed information and resources for their work, and the sources of information they consider most helpful. The degree to which participants were familiar with community resources varied widely across professionals and topic areas. Moreover, more than half of providers indicated they are sometimes or often unable to find needed information or assistance related to serving people with disabilities. The most helpful sources of disability information were said to be internet searches, conferences or workshops, and local/state disability organizations. We address implications for policy, practice, and research aimed at strengthening the pathways through which information is disseminated to individuals with disabilities and their families.

Dear Dr. Scott,

Thank you for the opportunity to revise our manuscript, *"Too Many Brick Walls": Perspectives on Accessing Disability Information and Resources Among Service Providers.* The reviewer's comments were very helpful in strengthening the manuscript. We detail below how we responded to each of the comments.

REVIEWER 1

The reviewer noted that the manuscript makes an important contribution and provides valuable information to both the research community and practitioners.

1. The reviewer suggested some wording revisions to a sentence in the abstract.

We have made this change.

2. The reviewer suggested shortening the second sentence of the literature review.

We agree it is a bit long. However, we have kept the sentence as is because it helps set up the array of valued life experiences we ask about in the survey. We have included citations in later sentences within the same paragraph that provide support for this statement. At the same time, we consider this to reflect common knowledge that does not necessarily need additional support.

3. The reviewer asked that we clarify the source of the quote in the second paragraph.

We have eliminated all but one citation and included this in the reference section.

4. The reviewer asked that we clarify what we mean by the disability service system.

We have revised this sentence so it now references to "disability service systems" in the plural. We agree that there are multiple systems that serve people with disabilities.

5. The reviewer suggested minor wording changes at the top of page 5.

We have made this change.

6. The reviewer asked that we clarify what we mean by disability service providers earlier in the introduction section.

We have defined this group more clearly on page 5. We note on page 7 that our sample for this paper does not include special educators working in K-12 schools or healthcare providers.

7. The reviewer asked that we explain the acronym pre-ETS.

We do so on page 6.

8. The reviewer asked what the average of 3.1 referenced.

We have clarified on page 7, that the average refers to the mean number of different areas in which they provided services or supports.

9. The reviewer asked where our list of different disabilities came from.

This list combined IDEA special education categories with additional disability categories suggested by our state leadership team. We now indicate this on page 10.

10. The reviewer asked the source of our various lists and noted that we referenced the wrong table.

We have described the source of these items (pages 10 and 11) and fixed the reference to Table 2.

11. The reviewer was curious about why we separated group by age for the first RQ, but not the others.

The experiences usually prioritized for children and adults are often quite different from each other. However, we did anticipate that key service needs would differ and so we included only a single list regardless of the age people served. The same rationale was used with regard to the helpful sources of information.

12. The reviewer suggested that we add the rural versus non-rural comparison to our list of research questions.

We have done so. This is now RQ5. The recommendation to include a fuller literature review regarding the rural factor is difficult, as this is not an issue that has been studied in our field. We have, however, incorporate a couple of related citations that point to how geography might impact service delivery. See page 12. We also include some discussion of this on page 6.

13. The reviewer asked what we were referencing when talking about an average of 5.0.

We have now clarified that this average was out of the 16 items we listed.

14. The reviewer wondered whether the connection between the diminished helpfulness of social media and participants' concerns about the accuracy and relevance of information.

This was a great insight. While we cannot link them directly in our data, they do indeed seem to go hand-in-hand. We now mention this possibility on page 19.

15. The reviewer suggested we address turnover in the literature review in order to tie it in more cohesively in the discussion.

We have opted not to mention this factor in the introduction, as we did not collect any data related to turnover. We do see it as an important context with regard to our implications, and so we mention it on page 21 of the discussion.

16. The reviewer suggested that we add more to the discussion regarding our rural versus non-rural findings.

We have elaborated on these findings on page 20 by adding an additional discussion point.

17. The reviewer suggested that we note in the limitations that this study was completed in a single state and other states may have differences in provider familiarity and knowledge as well as dissemination mechanisms.

We have added this limitation to page 22.

18. The reviewer noted that knowledge of services may be impacted by the availability of services and suggested we speak more to this possibility.

Excellent point. We now address this possibility on page 19.

19. The reviewer asked that we explain all acronyms upon first use.

We have made this change throughout.

20. The reviewer noted that our heading levels and Tables don't conform to APA 7th ed.

We have fixed these issues.

21. The reviewer suggested strengthening the literature review to that all of the findings and discussion points are foreshadowed.

We appreciate this suggestion. We have made several revisions based on the prior suggestions. Our introduction is about four pages in length and we are limited in the space we can add. We have reviewed all of the sections for alignment and feel that this is now much improved. Moreover, all of our research questions are set up in the introduction.

“Too Many Brick Walls”: Perspectives on Accessing Disability Information and Resources Among Service Providers

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Abstract

Disability service providers are often critical sources of guidance for individuals with intellectual and developmental disabilities (IDD) and their families. This study examined the extent to which these professionals were familiar with community resources that could help support the inclusion of individuals with IDD in valued experiences and help meet pressing service needs for families. We surveyed 294 service providers about their familiarity with disability-related resources, their experiences trying to access needed information and resources for their work, and the sources of information they consider most helpful. The degree to which participants were familiar with community resources varied widely across professionals and topic areas. Moreover, more than half of providers indicated they are *sometimes* or *often* unable to find needed information or assistance related to serving people with disabilities. The most helpful sources of disability information were said to be internet searches, conferences or workshops, and local/state disability organizations. We address implications for policy, practice, and research aimed at strengthening the pathways through which information is disseminated to individuals with disabilities and their families.

Keywords: intellectual and developmental disabilities, knowledge dissemination, information and referral services

“Too Many Brick Walls”: Perspectives on Accessing Disability Information and Resources Among Service Providers

Like anyone else, people with intellectual and developmental disabilities (IDD) want to be included fully in the life of their community. A meaningful job, lifelong learning, community involvement, good health, close friends, a place to contribute, someone to love, a vibrant faith, a safe place to live, a say in their own lives, and a sense of belonging—each are examples of the ordinary pursuits of people with and without disabilities. These universal aspirations are expressed in numerous studies examining the goals and dreams of people with IDD. For example, high school students with intellectual disability, autism, and multiple disabilities overwhelmingly indicate that they expect to obtain a paid job, live on their own, and/or obtain postsecondary education in early adulthood (Lipscomb et al., 2017). Likewise, within studies involving adults with IDD, participants often speak of the importance of relationships (e.g., Friedman & Rizzolo, 2018), their faith (e.g., Liu et al., 2014), their self-determination (e.g., Maggio et al., 2020), and their health (e.g., Caton et al., 2012), among other areas.

One purpose of disability service systems is to help promote this type of flourishing (Shogren & Turnbull, 2014). As emphasized in landmark legislation, disability policy in the United States is aimed toward “ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency” (e.g., Individuals with Disabilities Education Improvement Act, 2004). Professionals working in the disability field play a critical role in ensuring individuals with IDD have the opportunities, information, and services needed to be included in all aspects of community life. Their work has enduring importance in light of longstanding struggles to ensure people with IDD enjoy valued experiences and outcomes (e.g., Almalky, 2020; Bradley et al., 2020; Mason et al., 2021).

Promoting the flourishing of people with IDD is predicated (in part) on knowing about the services, supports, and programs they need across different aspects of their lives (Hodapp et al., 2018). Service providers and other professionals working with people with disabilities must be familiar with local and state resources that can be drawn upon to support community inclusion and valued outcomes for the individuals they serve. Indeed, these professionals are often the primary or sole source of reliable information and guidance for people with IDD and their families. Yet many parents describe the task of trying to identify needed services and supports as extremely difficult and often discouraging. For example, Gilson et al. (2017) surveyed 1,738 parents of children and adults with IDD about their familiarity with local programs addressing areas such as health, social relationships, recreation and leisure, work, housing, and family supports. The overwhelming majority indicated they had little or no knowledge of these much-needed resources.

The extent to which service providers are themselves familiar with available programs and services in their community has yet to be explored. Knowledge of these resources could help ensure professionals have access to the information and assistance they need to meet the multifaceted needs of individuals with IDD. Moreover, as primary conduits of information for parents and other caregivers, their own familiarity with local resources directly impacts the familiarity of families. New research is needed to identify areas in which service providers are (and are not) familiar with resources that could support the inclusion individuals with IDD in valued life experiences (e.g., finding and keeping a job, attending community events, living independently) and address their pressing service needs (e.g., assistive technology, behavior supports, mental health care). Studies focused on improving community-level service delivery for people with IDD often highlight the difficulties professionals, parents, and other community members alike face in sharing available resources effectively with one another (Bumble & Carter, 2021). Knowing more about how disability service providers (i.e., professionals who worked in organization, programs, or non-profits that serve individuals with disabilities and their families) characterize their own experiences trying to find needed resources could inform statewide efforts to disseminate information more seamlessly and successfully (e.g., Tucker et al., 2017).

It is also crucial that service providers remain well-informed about recommended practices, new policies, available services, and other issues related to their daily work. But it is unclear where these professionals are likely to turn when they need disability-related information or resources. Initial and ongoing training (e.g., workshops, conferences) is regularly advocated as a primary avenue for equipping direct service providers (e.g., Friedman, 2018; Remund et al., 2022). Likewise, professionals are likely to turn to their colleagues for insights and guidance. For example, large-scale studies of special education teachers and administrators have found that educators consider workshops, state conferences, and fellow teachers to be valued sources of information for their work (Brock et al., 2014; Knight et al., 2019). Such research should be extended to disability service providers to identify which sources of information they consider most helpful. Efforts to strengthen dissemination pathways could be informed by an understanding of what professionals consider to be the most helpful avenues.

Considerable variation, however, likely exists with regard to what service providers know about community resources and where they go for disability-related information. One source of variation may be the types of communities they serve. Rural communities can often differ from urban or suburban communities with regard to their disability resources and collaborations (Carter et al., 2021; Test & Fowler, 2018). For example, Awsumb et al. (in press) found significant differences in resources and knowledge related to pre-employment transition services (pre-ETS) within rural communities. It may be that other professionals working in rural communities (e.g., direct service providers) likewise report differences in their knowledge of resources. Another source of variation may be length of time professionals have worked in the field. As professionals gain more experience, they are likely to accrue more knowledge about available programs and services. Neither of these factors, however, has been studied in this area.

The purpose of this study was to examine disability service providers' familiarity with disability-related information and resources, as well as their experiences accessing needed information and resources. We addressed the following five research questions.

RQ1: How familiar are providers with resources related to supporting inclusion within everyday experiences valued by individuals with IDD and their parents?

RQ2: How familiar are providers with resources related to key service needs?

RQ3: How do providers characterize their experiences trying to access needed information and resources for their work?

RQ4: Which sources of information do providers consider most helpful?

RQ5: How do the answers to these questions vary based on the communities these professionals served (i.e., rural versus non-rural) or their experience in the field?

Method

This study was part of a larger statewide project aimed at understanding the disability-related information and resource needs of individuals with disabilities, families, and professionals. The mixed-method project combined surveys of more than 3,000 stakeholders across the state with follow-up focus groups involving 100 stakeholders. These stakeholders included individuals with disabilities; parents, siblings, and other loved ones; educators; service providers; state agency staff; and healthcare professionals. The present study centers on findings from surveys of disability service providers, not including special educators who work in K-12 schools or healthcare providers. The views of these latter two groups will be examined separately in future papers more specific to educational and medical contexts.

Participants

Participants were 294 disability service providers involved in supporting individuals with disabilities in Tennessee. To be included in this study, participants must have (a) currently worked in an organization, program, or non-profit that served individuals with disabilities and their families and (b) been 18 years of age or older. Sex and race/ethnicity of participants is displayed in Table 1. Their ages varied widely: 8.5% were between 20-29, 19.4% were between 30-39, 26.2% were between 40-49, 24.5% were between 50-59, 17.0% were between 60-69, and 3.7% were over 70; 0.7% chose not to report their age. Overall, their average years of experience in the field was 14.0 (*SD* = 11.8); almost one quarter (23.8%) had been in the field less than 5 years.

Recognizing that many providers support multiple areas of people’s lives, we asked about all the areas in which they provided services or supports. Responses included education (51.6%), behavioral (46.6%), employment/vocational (43.9%), family support (42.5%), transportation (26.9%), residential (25.2%), early intervention (23.1%), health (23.1%), and/or other (22.1%; e.g., legal advocacy, sports and recreation, financial, faith and religion). One quarter (28.6%) selected only one of these response options; the average number of areas in which they provided services or supports was 3.1 (*SD* = 1.9). Likewise, participants served individuals experiencing a range of disabilities (see Table 1). The majority (83.3%) of providers served individuals with intellectual disability and/or individuals with autism spectrum disorder. However, the average number of disability categories served was 7.8 (*SD* = 4.3). Many participants served individuals across different age levels, with the majority focused on adults (see Table 1).

Recruitment

We designed our measures and recruitment approaches in close collaboration with a leadership team comprised of representatives from eight state agencies, including the State Council on Developmental Disabilities. Our recruitment efforts spanned five months in the midst of the COVID-19 pandemic (December 2020 to April 2021). The broader project adopted a multifaceted approach to recruitment that combined paid and unpaid social media postings, newsletter announcements, email blasts, flyers, and presentations to key stakeholder groups. We worked with numerous state agencies (e.g., Departments of Education, Intellectual and Developmental Disabilities, Human Services/Vocational Rehabilitation, Mental Health), disability organizations (e.g., Arcs, Down Syndrome Associations, Autism societies, Centers for Independent Living, education and advocacy programs), service providers (e.g., employment and day programs, residential providers, behavioral health providers, transportation service providers), school districts, and community programs (e.g., Special Olympics, family support programs, sports and recreation). A variety of methods were utilized to identify recruitment partners. The leadership teams contributed ideas, we referenced statewide lists (e.g., VR providers, child development centers, professional associations), and we researched programs based on service area (e.g., transportation, therapies, pediatric clinics). We provided organizations with print and electronic flyers, sample social media posts, and email examples personalized for their organization. All recruitment materials included a link to the project's website, which provided study information and a link to the survey. Our final sample for the present paper included participants from more than half (58%) of the state's rural, urban, and suburban counties.

We took several steps to encourage high levels of participation. First, surveys were completed anonymously. Second, we offered the survey in three forms: online, print, or by phone. Third, we randomly selected 100 participants in the overall project to receive a $20 gift card to their choice of four businesses. Fourth, all participants could complete a separate survey to request free resources related to topics included in the survey.

Measures

We developed surveys to (a) examine participant familiarity with disability-related resources and services across multiple areas, (b) determine how they currently search for information and services, and (c) solicit recommendations for improving information and resource dissemination. We tailored the surveys for each stakeholder group involved in the overall project; however, they all addressed the same research questions. Drafts of surveys were reviewed by the state leadership team and piloted in advance of broad distribution. The final version of the survey could be completed online through REDCap (Harris et al., 2009), in print format, or over the phone; all disability service providers completed it online. We describe below those survey areas addressed in the present article.

Demographics

In addition to personal demographics (i.e., sex, race/ethnicity, age band), we asked participants to identify all of the areas in which they provided services to individuals with disabilities (e.g., behavioral, education, employment/vocational, family support, healthcare, residential, transportation, other), the type of communities in which the individuals with disabilities they serve live (i.e., rural, suburban, and/or urban), the number of years they have been working in the field, and their county. We asked two questions to characterize the individuals with disabilities whom they served in their work. First, participants selected all of the disabilities experienced by the individuals they serve, drawing from a fixed list that combined special education categories with additional disability groups identified by our state leadership team (e.g., autism spectrum disorder, intellectual disability, mental health; see Table 1). Second, we asked about the ages of the individuals with disabilities they serve (e.g., infants, children, youth, young adults, adults, and/or older adults). For both questions, multiple options could be selected and often were.

Resources Related to Valued Experience

We asked participants about their familiarity with community programs and services related to supporting everyday experiences valued by individuals with disabilities and their families. We presented them with a list of 13 experiences particularly relevant to children (e.g., doing well in school, having friends, learning social and communication skills; see Table 2) and a list of 19 items particularly relevant to youth and adults (e.g., finding or keeping a job, volunteering in the community; see Table 2). These two lists were generated by reviewing the literature, through discussions with our state leadership team, and through feedback from stakeholder groups. Participants completed either or both sections depending on whether they served individuals in those respective age bands. In our companion surveys of individuals with disabilities and of families, these same items were rated as important by large proportions of participants. We asked participants to rate their familiarity with community programs or services that could help in each area using a 4-point, Likert-type scale: 1 = *not at all familiar,* 2 = *a little familiar,* 3 = *somewhat familiar,* 4 = *very familiar.*

Resources Related to Service Needs

We asked participants about their familiarity with community programs and services related to common service needs often identified by individuals with disabilities and their families. We presented them with a list of 22 areas of assistance that might be needed by individuals and/or their families (e.g., assistive technology, behavior supports/services, respite care; see Table 3). 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 rate their familiarity with community programs or services that could help in each area using a 4-point, Likert-type scale: 1 = *not at all familiar*, 2 = *a little familiar,* 3 = *somewhat familiar,* 4 = *very familiar*. We then asked them to respond to the following open-ended prompt: List any other areas of disability programs or services that you wish you knew more about.

Experiences Accessing Needed Resources

We asked participants to indicate how often in the past year they needed information or assistance related to serving individuals with disabilities but did not know where to get it. Responses were provided on a 4-point, Likert-type scale: 1 = *never,* 2 = *rarely,* 3 = *sometimes,* 4 = *often.* As an open-ended, follow-up question we asked: What (if anything) makes it hard to find the information that you need?

Helpful Sources of Information

We asked participants about the sources of information or resources that they found helpful to inform their work. 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 4). Finally, we included the following open-ended prompt: Are there other sources of information you use that were not listed above?

Data Analysis

All close-ended questions on the online survey were required, providing us with 294 submitted surveys with no missing data. We used SPSS software (SPSS 26; IBM Corporation, 2019) for all analyses. For each research question, we summarized participant's responses by item using descriptive statistics (i.e., percentage, means, standard deviations). For RQ1, valued experiences were summarized separately for the two age categories—children (under 13) or youth and adults (13 and over)—as participants responded to either or both that were relevant to those they served. For RQ2, RQ3, and RQ4, we summarized all responses together as all items were the same regardless of age level.

In addition to the descriptive statistics, we undertook exploratory analysis across all research questions to examine the role community type and years of experience might have on participants' ratings. We used independent samples *t* tests to compare the responses of participants who only served individuals with disabilities in rural communities (*n* = 74) with participants served individuals in other types of communities (i.e., suburban and/or urban). We anticipated that professionals serving only rural communities would report less familiarity with resources related to valued experiences and service needs, more difficulty accessing needed information and resources, and consider their personal and collegial relationships (e.g., teachers, doctors, agency staff, local organizations) to be more helpful sources of information (e.g., Awsumb et al., in press; Test & Fowler, 2018). We then examined the magnitude of any differences by calculating Cohen's *d*. We divided the difference in group means by the pooled standard deviation. We also used Pearson correlations to examine the association with years of experience in the field. We anticipated that professionals with more experience would have more familiarity with available resources and have less difficulty accessing needed information and resources. For both 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. These analyses involved multiple comparisons and were considered exploratory.

We used thematic coding to examine responses to open-ended responses. Three graduate students and one undergraduate student were assigned to code all open-ended responses used in this article under the guidance of project staff and faculty. For each open-ended question, a coding framework comprised of thematic codes and definitions was created and 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.

Results

How Familiar Are Providers with Resources Related to Valued Experiences?

Children

At least half of participants indicated they were *somewhat* or *very familiar* with community resources that could help children with disabilities in 12 of the 13 experiences (see Table 2). They were most familiar with resources related to learning social and communication skills (*M* = 3.08), learning daily living skills (*M* = 2.99), and learning to make choices and decisions *(M* = 2.98). They were least familiar with resources focused on making friends (*M* = 2.67), participating in a faith community (*M* = 2.64), and attending summer camps/programs (*M*

= 2.47).

One difference was found based on community type (i.e., rural versus nonrural). Participants working in rural communities were significantly less familiar with resources related to attending summer campus/programs, $t(292) = -2.62$, $p = .012$. A significant, but small, positive correlation was found between years of experience and resource familiarity for nine areas: learning social and communication skills ($r = 0.12$, $p = .047$), learning daily living skills ($r = 0.14$, $p = .013$), being physically healthy ($r = 0.50$, $p = .013$), participating in recreational activities ($r = 0.12$, $p = .045$), attending community events ($r = 0.18$, $p = .002$), doing well in school ($r = 0.15$, $p = .008$), having friends ($r = 0.16$, $p = .008$), participating in a faith community ($r = 0.15$, $p = .010$), and attending summer camps/programs ($r = 0.13$, $p = .027$).

Youth and Adults

At least half of all participants indicated they were *somewhat* or *very familiar* with community resources related to 11 out of 19 experiences (see Table 2). They were most familiar with resources related to making their own choices and decisions ($M = 3.11$), advocating for others ($M = 3.06$), finding or keeping a job ($M = 3.06$), and having good mental health ($M = 3.06$). They were least familiar with resources focused on being a part of a cultural community ($M = 2.50$), dating ($M = 2.14$), and starting a family ($M = 1.94$).

No differences in resource familiarity were found based on community type (i.e., rural versus nonrural). A significant, but small, positive correlation was found between years of experience and resource familiarity for five areas: finding or keeping a job ($r = 0.14$, $p = .030$), going to college or technical school ($r = 0.14$, $p = .024$), having reliable transportation ($r = 0.13$, $p = .035$), being part of a faith community ($r = 0.13$, $p = .045$), and being part of a cultural community ($r = 0.16$, $p = .012$).

How Familiar Are Providers with Resources Related to Key Service Needs?

At least half of participants indicated they were *somewhat* or *very familiar* with resources that could help people with disabilities in 16 of the 22 areas of service need (see Table 3). They were most familiar with resources related to behavior supports and services ($M = 3.13$), mental health care ($M = 2.97$), and food assistance ($M = 2.91$). They were least familiar with resources related to benefits counseling ($M = 2.35$), parent or sibling support groups ($M = 2.35$), and childcare ($M = 2.25$). Additional disability programs or services that participants indicated they wished they knew more about related to housing (e.g., subsidized housing, residential options), resources for seniors, insurance (e.g., state medical insurance, support with applications), and advocacy (e.g., self-advocacy, education, medical).

Some differences were found based on community type. Educators working in rural communities were significantly more familiar with resources in the following service areas: mental health care, $t(292) = 2.23$, $p = .027$; food assistance, $t(292) = 2.58$, $p = .010$; and family counseling, $t(292) = 2.11$, $p = .036$. A significant, but small, positive correlation was found between years of experience and service need familiarity for six areas: food assistance ($r = 0.13$, $p = .026$), assistive technology ($r = 0.13$, $p = .024$), other therapies ($r = 0.12$, $p = .035$), disability evaluations ($r = 0.15$, $p = .011$), legal assistance ($r = 0.14$, $p = .016$), and childcare ($r = 0.14$, $p = .016$).

How Do Providers Describe Their Experiences Accessing Needed Information or Resources?

When asked how often they needed information or assistance related to serving individuals with disabilities, but did not know where to get it, 16.3% said never, 27.2% said rarely, 45.6% said sometimes, and 10.9% said often. There were no significant differences based on whether or not participants exclusively served rural communities (*p* = .571) and no significant association based on years of experience in the field (*p* = .085).

Additionally, we asked participants to identify what made it hard for them to find information on an open-ended survey question. One primary challenge was encountering incorrect information (e.g., out of date information; questions about trustworthiness) For example, one provider explained that “organizations do not update their websites often enough” and they often find “false or misleading information online.” Another participant indicated she had difficulty “knowing what is reliable information.” Another challenge related to the paucity of supports in particular locales. For example, participants cited “limited local resources” and “lack of resources in rural areas.” One participated explained, “The more local you get, the less there is a centralized listing of available supports. The state websites are the best place, but list organizations across the state, by default favoring population centers and not the more rural areas.” A third challenge was the absence of relevant resource (e.g., needed resource do not actually exist). For example, one participant lamented the “lack of resources for affordable transportation or housing” and another raised “mainly just the lack of certain types of services.” Other challenges included the overall organization of resources (e.g., lack of streamlined information or services, online information not tagged or categorized), desired information being difficult to find, financial constraints, and challenges connecting with resource providers (e.g., talking to a live person, finding the right person).

Which Sources of Information Do Providers Consider Most Helpful?

For 14 of the 16 sources of information, at least half of participants considered each to be *somewhat* or *very helpful* (see Table 4). They rated the following sources as most helpful: internet searches (*M* = 3.34), conferences or workshops (*M* = 3.32), and local/state disability organizations (*M* = 3.22). The least helpful resources included social media (*M* = 2.56), podcasts (*M* = 2.15), and blogs (*M* = 2.04). Overall, they considered an average of 5.0 different sources of information to be *very helpful* out of the 16 items we listed. The items most often ranked among the top three sources of information were internet searches (22.8%), local/state disability organizations (12.1%), staff from state agencies or programs (11.6%), and conferences or workshops (11.5%).

No differences were found based on community type. No significant correlations were found between years of experience and ratings of helpfulness.

Discussion

Formal service systems can play a critical role in promoting the flourishing of people with IDD and their families. Moreover, inclusion in various aspects of community life can be advanced by having access to information about relevant community resources and opportunities. This study explored the extent to which disability service providers are familiar with local resources across an array of important areas. Specifically, we examined where these professionals go for disability-related information and their awareness of what might be available. Our findings provide several new insights into the importance and complexities of information dissemination in the disability field.

Considerable variability was evident in the extent to which service providers were familiar with community resources that could help support valued experiences for children, youth, and adults with disabilities. In many of the areas addressed in our survey, at least half of participants indicated having more than minimal (i.e., not at all or a little) awareness of relevant resources. This was particularly the case in areas such as addressing social and communication skills, choice and decision-making, mental or physical health, employment, and recreational activities. Each reflects areas in which the full participation of individuals with IDD has historically and presently been limited (Agran et al., 2014). Such findings are encouraging, as these professionals often serve as trusted guides and connectors for individuals with IDD and their families.

At the same time, a moderate percentage of service providers also indicated they were not at all or only a little familiar with resources in each of the areas (range, 24% to 69% across all areas). This was particularly true in areas related to community involvement (e.g., independent living, being part of a faith or cultural community) and relationships (e.g., dating, starting a family, making friends). For individuals or families who have questions about supports in these important areas, some providers may be less certain about how to respond. Lower familiarity is likely due in part to the fact that some providers have a narrower scope of service delivery or expertise (e.g., employment supports, behavioral supports). As a result, they may have received less training on or exposure to community resources addressing other life domains. Indeed, providers who have been in the field longer tended to report significantly higher levels of familiarity related to a number of these areas.

A similar portrait emerged when it came to the key service needs of individuals and families. Wide variations were apparent within and across service providers. In other words, individual participants tended to be more familiar with resources in some areas and less familiar with resources in others. For example, only 14% of participants indicated they were somewhat or very familiar with resources that could support *all* 22 key service needs. Although it would be surprising for any professional to be fluent in every area, it is still helpful for service providers to know who else they can point families to when needs arise. Likewise, familiarity varied across areas of service need. Greater familiarity was found in the areas of behavioral supports, mental health care, food assistance, and various therapies (e.g., occupational therapy, physical therapy, speech). But resources related to family supports (e.g., respite, family counseling, childcare, support groups) and some medical needs (e.g., medical equipment, accessible dental care) were much less well known. Each of these latter areas have been raised as points of struggle for many families (e.g., Gerreth & Borysewicz-Lewicka, 2016; Pilapil et al., 2017). It is also possible that limited familiarity was sometimes due to limited availability of particular services. In other words, participants may not have known about services because those services simply do not exist.

Overall, many participants indicated that accessing needed information or assistance related to serving individuals with disabilities was quite difficult. Specifically, more than half (57%) of service providers indicated they sometimes or often did not know where to get this information or assistance; very few (16%) said this never occurred. Easing the difficulties with locating disability-related information is a focus of a growing number of states (e.g., Hodapp et al., 2018). Although service providers need not be experts in every conceivable area, they should be familiar with other community organizations or state-level initiatives that could provide this guidance when needed. For example, Tennessee has developed a statewide online information and referral system called Tennessee Disability Pathfinder (www.tnpathfinder.org) that organizes available resources by county, topic, diagnosis, and life stage. However, awareness of this robust resource remains uneven among local service providers.

Service providers identified multiple sources of disability information they considered to be helpful in their professional work. Not surprisingly, Internet searches emerged as the top-rated source across participants and community types. Although the ease and ubiquity of this option contributes to its accessibility, the accuracy and salience of search findings are not always certain and depends on the quality of keyword tagging. Indeed, the prevailing challenge with searches surrounds discerning which findings are most relevant and worth sharing. Conferences and workshops were considered similarly helpful (cf., Brock et al., 2014). These training venues may be more likely to address best practices and relevant services, particularly if hosted locally and led by experts. Finally, local and state agencies were also affirmed as helpful sources of disability information. Their knowledge of the local landscape and direct charge to resource local professionals makes them a compelling resource. In contrast, new media (e.g., social media, podcasts, blogs) has not yet garnered broad appeal among providers. This could be connected in part to their concerns about the inaccuracy or relevance of information.

Finally, we were surprised that locale was not a more salient factor in relation to resource familiarity, ease in locating resources, or the helpfulness of various information sources. Indeed, differences for rural service providers were found in few areas and almost always in the direction of greater familiarity. This may be because many service providers receive the same training and support from state agencies (e.g., vocational rehabilitation, department of intellectual and developmental disabilities, department of children’s services), regardless of where they work. In contrast, years of experience was often correlated with greater familiarity across a number of different areas. This was expected, as providers are likely to learn more about what is available in their community as they support more individuals and collaborate with more partners over time.

Implications for Policy and Practice

Our findings have several implications for policy and practice. First, service providers will benefit from training and guidance regarding the breadth of local resources that might have relevance to the individuals and families they serve. The more challenging question surrounds when and how best to address these topics. The initial onboarding of staff provides one context for introducing general information about go-to sources in a state. In addition, more targeted information could be rolled out over time within ongoing professional development, workshops, lunch-and-learns, newsletters, and other just-in-time strategies. Second, turnover among service providers remains high and concerning (Houseworth et al., 2020). As a result, it will be necessary for disability agencies and organizations to regularly revisit their efforts to equip and support staff in this area. One-time efforts are likely to be insufficient. Even in the absence of turnover, the changing nature of community resources warrants regularly revising over time. Third, these findings highlight the importance of and need for strong informational and referral systems within states and regions. This requires a strong fiscal investment within a state, along with shared commitment from multiple state agencies and numerous local programs to ensure information remains updated and is disseminated widely (Hodapp et al., 2018). Disability-related programs, services, supports, policies, and best practices are often in flux and require regular revisiting. Fourth, peer-mediated pathways for connecting providers with information about resources may be valued and promising. Turning to fellow providers for occasional input and guidance is likely common practice, but could be enhanced by establishing peer networks, communities of practice, or other relational forums.

Limitations

Several limitations to this study warrant consideration. First, as is true in most states, no complete list of disability providers and professionals was available in Tennessee. As a result, we relied on local agencies and organizations to distribute study announcements to their staff on our behalf. This may have led to inconsistency in which staff ultimately heard about the study and participated. Second, ratings of resource familiarity were personal estimates made by participants. Some of the variability in our findings may be due to differences in how each participant interpreted of the response options (i.e., not at all, a little, somewhat, and very familiar) and their point of reference when doing so (e.g., compared to others or to their desired familiarity). Third, we have no way of gauging the accuracy of participants' ratings of familiarity and helpfulness. We strived to promote honest appraisals by allowing participants to complete the survey anonymously, omitting questions about their specific employer, and assuring them that their responses would not be identifiable. However, it may be that ratings of familiarity and helpfulness are biased in more positive directions than they really are. Fourth, some service providers may also have been parents or siblings of family members with IDD. In such cases, they may have instead chosen to complete a different version of the survey if they identified as having multiple roles. This possibility could have limited our overall participation. Fifth, this study was conducted in a single state. The roles and training of disability service providers varies from state to state, as do statewide approaches to dissemination. As a result, the familiarity and preferences of providers may look different elsewhere.

Future Research

Findings from this study suggest several avenues for future research. First, more information is needed about the steps taken by disability professionals who have been especially successful in finding needed information and resources. Follow-up interviews with service providers who provided high ratings of familiarity could yield insights into what strategies they have found to be successful. Second, the ways in which disability agencies provided training and support to their staff in this area—as well as the effectiveness of such efforts—warrants exploration. Much more guidance is needed for organizations regarding how best to equip and support their staff in this area. Third, wide variations in disability resources exist across states, as is true of their approaches to information and referral. Examining these variations and their implications could provide guidance to states interested in strengthening their dissemination pathways. States that shine in this area could serve as examples for other states with less developed approaches. Fourth, the degree to which service provider’s knowledge of community resources leads to better outcomes is a critical question. If knowing more about available options translates into improved experiences and outcomes for individuals with IDD and their families, local and state agencies may be inclined to invest more heavily in strengthening dissemination pathways.

Conclusion

Individuals with IDD and their families can benefit immensely from the guidance they obtain through their service providers. However, those providers must themselves be familiar with information and community resources related to the valued experiences and service needs of their clients. Findings from this study highlight areas of strength and need related to information access among disability service providers. We encourage continued efforts within the field to strengthen the pathways through which information is disseminated to individuals and families.

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Table 1

Participant Demographics and Individuals Served

Variable	*n*	%
Sex		
Female	247	84.0
Male	46	15.6
Prefer not to answer	1	0.3
Race/ethnicity[a]		
American Indian and Alaska Native	9	3.1
Asian	3	1.0
Black or African American	41	13.9
Hispanic/Latino	8	2.7
Native Hawaiian & Other Pacific Islander	0	0.0
White	234	79.6
Other	5	1.7
Prefer not to answer	6	2.0
Types of disabilities among individuals whom participants serve[a]		
Autism spectrum disorder	205	69.7
Deaf-blindness	116	39.5
Deafness	120	40.8
Developmental delay	202	68.7
Hearing impairment	166	56.5
Learning disability	181	61.6
Intellectual disability	215	73.1
Mental illness, mental health disorder, or emotional disabilities	198	67.3
Other health impairment or ADD/ADHD	152	51.7
Physical disability	188	63.9
Speech/language impairment	176	59.9
Traumatic brain injury	123	41.8
Visual impairment	146	49.7
Substance abuse disorder	84	28.6
Age of individuals with disabilities whom participants serve[a]		
Infants (under 2)	79	26.9
Children (2-12)	128	43.5
Youth (13-18)	125	42.5
Young adults (19-25)	186	63.3
Adults (25-65)	198	67.3
Older adults (65+)	154	52.4
Type of communities in which participants serve[a]		
Rural	236	68.2
Suburban	217	62.7
Urban	181	52.3

[a] More than one option could be selected; total percentages exceed 100%.

Table 2

Provider Familiarity with Resources to Support Valued Experiences

	Percentage responding					Factors	
Item	Not at all familiar	A little familiar	Somewhat familiar	Very familiar	*M* (*SD*)	Rural[a]	Years in field[b]
Children (*n* = 294)							
Learning social and communication skills	9.9	15.6	31.0	43.5	3.08 (0.99)	-.09	.12*
Learning daily living skills	10.5	19.4	30.6	39.5	2.99 (1.00)	.03	.14*
Learning to make choices and decisions	11.2	20.1	28.2	40.5	2.98 (1.03)	-.14	.10
Having good mental health	10.5	23.8	31.0	34.7	2.90 (1.00)	-.07	.08
Being physically healthy	10.5	24.8	31.6	33.0	2.87 (0.99)	-.12	.12*
Participating in recreational activities	12.2	21.1	35.4	31.3	2.86 (1.00)	-.11	.12*
Attending community events	11.9	23.1	35.7	29.3	2.82 (0.99)	-.08	.18*
Being part of their local community	12.6	21.8	37.4	28.2	2.81 (0.99)	-.14	.07
Experiencing personal growth	15.6	21.1	36.7	26.5	2.74 (1.02)	-.19	.04
Doing well in school	15.3	26.5	33.3	24.8	2.68 (1.01)	-.03	.15*
Having friends	17.0	23.5	35.0	24.5	2.67 (1.03)	.01	.16*
Participating in a faith community	15.6	28.9	31.6	23.8	2.64 (1.01)	-.03	.15*
Attending summer camps/programs	19.7	32.7	28.6	19.0	2.47 (1.01)	-.31*	.13*
Youth and adults (*n* = 251)							
Making their own choices and decisions	7.2	17.5	32.3	43.0	3.11 (0.94)	-.16	.11
Advocating for others	8.8	19.1	29.5	42.6	3.06 (0.98)	-.12	.09
Finding or keeping a job	6.0	21.9	32.7	39.4	3.06 (0.92)	-.01	.14*
Having good mental health	8.0	15.5	38.6	37.8	3.06 (0.92)	-.07	.01
Participating in recreation/leisure activities	8.4	18.7	39.8	33.1	2.98 (0.93)	.01	.03
Volunteering in the community	7.6	22.7	33.1	36.7	2.99 (0.95)	-.26	.05
Being physically healthy	7.6	17.9	44.6	29.9	2.97 (0.89)	-.12	.06
Pursing personal growth	11.2	16.3	39.4	33.1	2.94 (0.97)	-.15	.09
Feeling part of a community	8.4	19.5	42.2	29.9	2.94 (0.91)	-.19	.06
Attending community events	9.2	22.3	38.6	29.9	2.89 (0.94)	-.20	.09
Making friends	10.0	20.7	39.8	29.5	2.89 (0.94)	-.03	.09
Going to college or technical school	12.7	23.1	33.9	30.3	2.82 (1.01)	-.10	.14*
Having reliable transportation	14.3	21.5	32.7	31.5	2.81 (1.04)	.13	.13*
Managing money well	16.3	20.3	39.0	24.3	2.81 (1.01)	.03	.12
Having their own place to live	9.6	27.5	37.8	25.1	2.78 (0.93)	.10	.02
Being part of a faith community	14.3	26.7	33.5	25.5	2.70 (1.01)	.01	.13*
Being part of a cultural community	19.9	28.3	33.5	18.3	2.50 (1.01)	-.16	.16*
Dating	34.7	29.1	24.3	12.0	2.14 (1.03)	-.05	.09
Starting a family	44.2	25.1	22.7	8.0	1.94 (0.99)	.16	.10

[a]Cohen's *d*. [b]Pearson's *r*.

*$p < .05$.

Table 3

Provider Familiarity with Resources to Support Key Service Needs

	Percentage responding					Factors	
Item	Not at all familiar	A little familiar	Somewhat familiar	Very familiar	*M* (*SD*)	Rural[a]	Years in field[b]
Behavior supports/services	4.4	17.3	38.8	39.5	3.13 (0.85)	.18	.05
Mental health care	10.2	21.8	29.3	38.8	2.97 (1.01)	.30*	.07
Food assistance	11.9	18.0	37.4	32.7	2.91 (0.99)	.35*	.13*
Occupational therapy	11.9	25.2	31.6	31.3	2.82 (1.01)	.07	.10
Speech therapy	13.6	23.1	31.6	31.6	2.81 (1.03)	-.01	.10
Physical therapy	13.6	24.1	31.0	31.3	2.80 (1.03)	.10	.10
Assistive technology	13.9	24.1	33.7	28.2	2.76 (1.01)	-.09	.13*
Financial assistance	15.6	23.1	41.2	20.1	2.66 (0.97)	.17	.10
Early intervention services	20.4	22.8	27.9	28.9	2.65 (1.10)	.02	.07
Other therapies	17.3	27.9	27.9	26.9	2.64 (1.06)	.07	.12*
In-home care	18.4	28.6	26.2	26.9	2.62 (1.07)	.06	.07
Interpretation or translation services	19.7	25.5	29.9	24.8	2.60 (1.07)	-.24	.05
Accessible medical care	17.3	29.6	28.6	24.5	2.60 (1.04)	.24	.04
Disability evaluations	19.0	24.5	34.4	22.1	2.60 (1.03)	-.02	.15*
Family counseling	17.3	32.0	31.6	19.0	2.52 (0.99)	.29*	.10
Legal assistance	22.1	26.5	30.6	20.7	2.50 (1.05)	.07	.14*
Respite care	19.7	33.0	27.6	19.7	2.47 (1.02)	-.13	.08
Accessible dental care	23.1	30.3	27.2	19.4	2.43 (1.05)	.16	.08
Medical equipment	25.2	26.5	30.3	18.0	2.41 (1.05)	.13	.10
Benefits counseling	29.9	24.5	26.2	19.4	2.35 (1.10)	-.01	.09
Parent or sibling support groups	21.8	35.7	28.6	13.9	2.35 (0.97)	-.17	.07
Childcare	31.0	28.2	25.9	15.0	2.25 (1.05)	.14	.14*

[a]Cohen's *d*. [b]Pearson's *r*.

Table 4

Provider Ratings of the Helpfulness of Various Sources of Information

	Percentage responding					Factors	
Item	Not at all helpful	A little helpful	Somewhat helpful	Very helpful	*M* (*SD*)	Rural[a]	Years in field[b]
Internet searches	2.0	11.6	37.1	49.3	3.34 (.076)	-.03	-.01
Conferences or workshops	3.7	12.6	31.6	52.0	3.32 (0.83)	-.04	.02
Local/state disability organizations	6.5	11.9	35.0	46.6	3.22 (0.89)	-.08	.03
Staff from state agencies or programs	6.8	14.6	35.4	43.2	3.15 (0.91)	.07	.11
Families I work with	6.5	14.3	37.8	41.5	3.14 (0.89)	-.25	-.03
Teachers or other school staff	15.3	20.4	35.7	28.6	2.78 (1.03)	-.18	.06
Doctors, therapists, or other medical professionals	8.2	22.8	35.7	33.3	2.94 (0.94)	.-04	.04
Friends	5.8	26.2	39.8	28.2	2.90 (0.88)	-.13	-.02
National disability organizations	12.2	22.1	33.7	32.0	2.84 (1.01)	-.19	.07
Research articles or journals	11.2	25.2	34.0	29.6	2.82 (0.98)	-.15	.02
Online videos	10.2	26.9	36.7	26.2	2.79 (0.95)	-.06	-.04
Books	16.3	29.6	32.7	21.4	2.59 (1.00)	-.07	-.01
Social media (like Facebook, Twitter, or Instagram)	17.3	27.9	36.1	18.7	2.56 (0.99)	-.10	-.08
Podcasts	33.0	31.0	24.1	11.9	2.15 (1.01)	-.09	-.01
Blogs	36.1	31.6	24.8	7.5	2.04 (0.95)	-.13	-.07

[a]Cohen’s *d*. [b]Pearson’s *r*

Dear Dr. Scott,

Thank you for the opportunity to revise our manuscript, *"Too Many Brick Walls": Perspectives on Accessing Disability Information and Resources Among Service Providers.* The reviewer's comments were very helpful in strengthening the manuscript. We detail below how we responded to each of the comments.

REVIEWER 1

The reviewer noted that the manuscript makes an important contribution and provides valuable information to both the research community and practitioners.

1. The reviewer suggested some wording revisions to a sentence in the abstract.

We have made this change.

2. The reviewer suggested shortening the second sentence of the literature review.

We agree it is a bit long. However, we have kept the sentence as is because it helps set up the array of valued life experiences we ask about in the survey. We have included citations in later sentences within the same paragraph that provide support for this statement. At the same time, we consider this to reflect common knowledge that does not necessarily need additional support.

3. The reviewer asked that we clarify the source of the quote in the second paragraph.

We have eliminated all but one citation and included this in the reference section.

4. The reviewer asked that we clarify what we mean by the disability service system.

We have revised this sentence so it now references to "disability service systems" in the plural. We agree that there are multiple systems that serve people with disabilities.

5. The reviewer suggested minor wording changes at the top of page 5.

We have made this change.

6. The reviewer asked that we clarify what we mean by disability service providers earlier in the introduction section.

We have defined this group more clearly on page 5. We note on page 7 that our sample for this paper does not include special educators working in K-12 schools or healthcare providers.

7. The reviewer asked that we explain the acronym pre-ETS.

We do so on page 6.

8. The reviewer asked what the average of 3.1 referenced.

We have clarified on page 7, that the average refers to the mean number of different areas in which they provided services or supports.

9. The reviewer asked where our list of different disabilities came from.

This list combined IDEA special education categories with additional disability categories suggested by our state leadership team. We now indicate this on page 10.

10. The reviewer asked the source of our various lists and noted that we referenced the wrong table.

We have described the source of these items (pages 10 and 11) and fixed the reference to Table 2.

11. The reviewer was curious about why we separated group by age for the first RQ, but not the others.

The experiences usually prioritized for children and adults are often quite different from each other. However, we did anticipate that key service needs would differ and so we included only a single list regardless of the age people served. The same rationale was used with regard to the helpful sources of information.

12. The reviewer suggested that we add the rural versus non-rural comparison to our list of research questions.

We have done so. This is now RQ5. The recommendation to include a fuller literature review regarding the rural factor is difficult, as this is not an issue that has been studied in our field. We have, however, incorporate a couple of related citations that point to how geography might impact service delivery. See page 12. We also include some discussion of this on page 6.

13. The reviewer asked what we were referencing when talking about an average of 5.0.

We have now clarified that this average was out of the 16 items we listed.

14. The reviewer wondered whether the connection between the diminished helpfulness of social media and participants' concerns about the accuracy and relevance of information.

This was a great insight. While we cannot link them directly in our data, they do indeed seem to go hand-in-hand. We now mention this possibility on page 19.

15. The reviewer suggested we address turnover in the literature review in order to tie it in more cohesively in the discussion.

We have opted not to mention this factor in the introduction, as we did not collect any data related to turnover. We do see it as an important context with regard to our implications, and so we mention it on page 21 of the discussion.

16. The reviewer suggested that we add more to the discussion regarding our rural versus non-rural findings.

We have elaborated on these findings on page 20 by adding an additional discussion point.

17. The reviewer suggested that we note in the limitations that this study was completed in a single state and other states may have differences in provider familiarity and knowledge as well as dissemination mechanisms.

We have added this limitation to page 22.

18. The reviewer noted that knowledge of services may be impacted by the availability of services and suggested we speak more to this possibility.

Excellent point. We now address this possibility on page 19.

19. The reviewer asked that we explain all acronyms upon first use.

We have made this change throughout.

20. The reviewer noted that our heading levels and Tables don't conform to APA 7th ed.

We have fixed these issues.

21. The reviewer suggested strengthening the literature review to that all of the findings and discussion points are foreshadowed.

We appreciate this suggestion. We have made several revisions based on the prior suggestions. Our introduction is about four pages in length and we are limited in the space we can add. We have reviewed all of the sections for alignment and feel that this is now much improved. Moreover, all of our research questions are set up in the introduction.