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## Family Perspectives on Pursuing Employment for Adults with Intellectual and Developmental Disabilities

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### **Abstract**

The road to employment is not often easy for individuals with intellectual and developmental disabilities (IDD). Families know firsthand the complexities and challenges of obtaining employment for their members with extensive support needs. The purpose of this qualitative study was to identify the critical barriers they encounter in this important pursuit. We interviewed 60 parents (and other caregivers) whose family members with intellectual disability and/or autism had sought and/or obtained paid work. The difficulties they described were extensive and multifaceted. Specifically, participants identified 64 different barriers attributed to six primary areas: individuals, families, schools, service systems, workplaces, and communities. Their unique insights amplify the need for new approaches for promoting integrated employment. We offer recommendations for research and practice aimed at better understanding and ameliorating barriers to meaningful work for adults with IDD.

*Keywords:* barriers, integrated employment, intellectual disability, autism, attitudes

Family Perspectives on the Complexities of Pursuing Employment  
for Adults with Intellectual and Developmental Disabilities

The advantages of integrated employment abound for individuals with intellectual and developmental disabilities (IDD). Obtaining a job in the community that offers typical wages alongside fellow co-workers without disabilities can bring an array of substantive benefits. Most obviously, a regular paycheck and good benefits provide financial resources to meet personal needs and participate in the life of the community. In addition, integrated employment can lead to new friendships and other social connections; it can provide a source of purpose, pride, and personal achievement; and it offers a context for being challenged and growing personally (Allen et al., 2019). Not surprisingly, large majorities of youth and adults with IDD aspire to work in their community (Lipscomb et al., 2017; National Core Indicators, 2018). This common pursuit also aligns with the expectations of many of their parents and family members (Gilson et al., 2018; Turnbull & Turnbull, 2015).

Yet, the employment outcomes of individuals with IDD have long lagged behind their vocational aspirations (see review of outcomes by Almalky, 2020). National employment rates for these adults have ranged from 18-21% over the last decade (Winsor et al., 2021). Despite the Americans with Disabilities Act in 1990 and the introduction of federal transition mandates within the Individuals with Disabilities Education Act (IDEA), employment outcomes for youth and adults with IDD have remained stagnant and always uncertain (Wehman et al., 2021). It is critical to identify the array of factors that still stand in the way of so many people pursuing their goals of joining the workforce. As new strategies or interventions are developed and tested, it remains equally important to pinpoint those enduring or emerging barriers that must be addressed concurrently in order to elevate the employment outcomes of adults with IDD?

Parents and other caregivers know first-hand the challenges and complexities of pursuing

work for their family members with IDD. This is particularly true when their family members have more extensive support needs. Parents remain one of the few constants amidst changing service systems (e.g., moving from school to adult services) and support staff (e.g., teachers, job coaches, vocational rehabilitation staff, direct support providers) across the lifespan. As a result, they are frequently on the forefront of any efforts to find and maintain integrated employment. The intensity of their family member's support needs often requires parents or siblings to play a prominent role in locating job opportunities, approaching employers, recruiting supports, managing paperwork, and providing transportation (e.g., Francis et al., 2014). Their views from the frontlines of this often-exhausting endeavor could provide important insights to a field that is directly charged with improving employment outcomes (Individuals with Disabilities Education Improvement Act, 2004; Workforce Innovation and Opportunity Act, 2014). In other words, knowing the barriers families currently encounter can directly inform the development of new practices, programs, and policies that ameliorate these barriers.

Numerous studies have addressed the barriers to integrated employment encountered by professionals (e.g., special educators, providers, employers; Awsumb et al., 2020; Carter et al., 2021; Reisen et al., 2014; Trainor et al., 2008). Their concerns have centered on the skills of individuals with IDD, the expectations of families, the attitudes of employers, and the competencies of staff. However, the views of families have been less prominent. Several recent studies have queried parents about the challenges they experience and expect when supporting the employment pursuits of their family member with IDD. Francis et al. (2014) surveyed 68 families who attended a two-day employment awareness training, asking them to identify the top five barriers they believed impacted community employment. Among the 27 different barriers they named the most common were poor social skills, the need for extensive support, the lack of agency support, disability severity, and lack of employer flexibility. Gilson et al. (2018) also

surveyed parents and other close relatives ( $n = 673$ ), asking them whether each of 14 factors might deter their family member with IDD from finding and maintaining a job. Although every factor was affirmed by the most participants, the most pressing concerns were opportunities for on-the-job support, the ability to apply for and find a job, the ability to be hired by an employer, social and communication skills, safety on the job, lack of reliable transportation, and the ability to perform the job. In their interviews with 21 parents of transition-age youth with autism, Sosnowy et al. (2018) heard several prominent barriers, including lack of job opportunities, difficulties finding positions that matched their child's interests and skills, and challenges identifying workplaces and employers who were truly supportive. Finally, Carter et al. (2018) analyzed findings from a series of regional community conversation events focused on the state's conversion from sheltered to integrated employment. Among the 35 distinct reasons parents said they were reluctant to pursue community employment, the most prominent were safety concerns, insufficient supervision, lack of community acceptance, and transportation barriers. Each of these studies provides much-needed insights into the constellation of factors that can stand in the way of integrated employment. At the same time, they are limited in their reliance on surveys, the brevity with which interview findings were presented (e.g., limited quotes or context), or their narrower focus on specific types of barriers. A broader and more nuanced list of prevailing employment barriers is needed to inform the development of comprehensive interventions that address the array of obstacles families encounter in their pursuit of work.

The purpose of this qualitative study was to explore the perspectives of families on their pursuit of integrated employment. It comprised the first phase of a multi-year intervention development project focused on equipping and supporting parents to pursue integrated employment for their family members with IDD. Therefore, we wanted to develop a thorough compilation of the multiple factors that can limit employment outcomes for their family

members with IDD. Through interviews with dozens of different people representing diverse communities, backgrounds, and family situations, we addressed the following research questions. What barriers are said to hinder access to integrated employment for youth and adults with IDD? What factors are associated with these barriers?

## **Method**

### **Participants**

Participants were 60 parents or primary caregivers (i.e., 55 parents, 4 siblings, 1 grandparent) of individuals with IDD. To be included, participants must have been at least 18 years of age, lived in [state masked], and had a working-age family member (age 16-65) with IDD. Participants ranged in age from 24 to 81 years ( $M = 55.6$  years,  $SD = 10.6$ ). Most (81.7%) were female and 17% lived in rural communities. Additional demographic information (e.g., age, highest level of education, race/ethnicity) is presented in Table 1.

The individuals in their family who had IDD ranged in age from 16 to 60 ( $M = 26.8$  years;  $SD = 9.5$ ). The majority (63%) was male. According to participants, half (50%) had an intellectual disability and a third (33.3%) had autism; 16.7% had both. Many were said to also have secondary disabilities (e.g., speech/language impairments, orthopedic impairment). Although 84.6% of individuals with IDD were employed for pay at some time in the past, only 45% were employed for pay in their community at the time of the study. This latter employment rate was minimally impacted by the onset of the pandemic midway through the study. When asked how they would describe their family member's degree of impairment, 25.0% said mild, 58.3% said moderate, and 16.7% said severe.

### **Recruitment**

Our team actively sought parents and other caregivers who had diverse backgrounds (e.g., race/ethnicity, education level), who resided in an array of communities (e.g., rural to

urban), and whose family members had varied employment experiences (e.g., formerly, currently, or never employed) and support needs (e.g., less to more intensive). This required us to adopt a multi-pronged approach to recruitment that combined broad announcements, targeted invitations, and snowball sampling. We engaged our project advisory committee and partnered with numerous formal services, disability organizations, and community programs in these efforts. A total of 53 disability- and family-focused organizations agreed to distribute recruitment materials to their constituents using project-created flyers, email invitations, social media announcements, and electronic newsletters blurbs. These organizations included disability advocacy groups, inclusive higher education programs, parent and sibling groups, Arc chapters, disability ministries, and disability-focused sport/recreation groups within the state. We asked these partners to use the dissemination methods that best fit with their organization's outreach efforts, while also tracking which approaches they selected. Recruitment spanned six months and was concluded when we began to see saturation (i.e., new barriers were rarely emerging) and our sample was sufficiently diverse (i.e., race/ethnicity resembled state demographics). All procedures received Institutional Review Board (IRB) approval. We interviewed all 60 parents or primary caregivers who met our inclusion criteria; no interested participants were turned away.

## **Procedures**

We used a combination of individual interviews ( $n = 31$ ) and focus groups ( $n = 6$ ) to solicit the views and recommendations of participants. We asked participants to indicate their preference for format, recognizing that some might feel more comfortable sharing their stories within a one-on-one versus group context. The onset of the COVID-19 pandemic midway through the study required us to adapt our plans for in-person interviews. For individual interviews, three were held in person, nine were held over the phone, and 19 were held using a

video conferencing platform (i.e., Zoom). Individual interviews averaged 55 min in length (range, 19-102 min). We held four focus groups in-person at various locations (e.g., disability advocacy organization, community-based day program, university) and held two online using Zoom. Focus group size ranged from 2 to 7 participants ( $M = 5$ ); the smallest group was due to last-minute cancellations. Focus groups averaged 99 min in length (range, 91-108 min).

Two members of the project team facilitated all interviews, both of whom had advanced degrees, extensive experience in the areas of disability or employment, and prior experience facilitating focus groups. An additional team member took notes at focus groups to capture who was speaking and any relevant body language. We developed a semi-structured interview protocol (available by request) based on prior research (e.g., Francis et al., 2014; Gilson et al., 2018; Kramer et al., 2018) and our goal of eliciting a comprehensive list of employment barriers. Each interview began with introductions, a reminder of the study's purpose, and an emphasis of key procedural points (e.g., assurance their identifying information would not be shared, encouragement to voice different perspectives, reminder to respect confidentiality). We asked a series of questions addressing four core areas: (a) the importance and conceptualization of employment for their family member with IDD; (b) barriers to integrated employment for their family member; (c) facilitators of integrated employment for their family member, and (d) recommendations for our intervention development. For the present paper, the most relevant interview protocol questions were: *What things might make it hard for your family member to find or keep integrated employment? Which of these barriers do you consider to be the most challenging? Why? Are any of these barriers "deal breakers"?* However, discussion of barriers naturally occurred throughout the interviews. We used follow-up questions and probes (e.g., Tell me more about that issue. Can you share any examples? Have you encountered barriers related to [area]?) for clarification, elaboration, and to obtain more detail.



## **Data Analysis**

We began by ensuring all audio recordings were professionally transcribed, checked for accuracy, and thoroughly de-identified. We then adopted a team-based approach (Patton, 2015) to coding that involved two project staff (who conducted the interviews); four graduate students studying in the areas of special education, psychology, and counseling; and one faculty member with expertise in integrated employment. Two additional faculty members with expertise in families, disability, and employment—one of whom is the parent of an employed son with IDD—also reviewed the emerging codes and barriers to provide feedback regarding their clarity and salience. We all share a deep commitment to ensuring individuals with IDD have the opportunities and support to contribute meaningfully within the workplace of their choice. We also believe that the first-hand experiences and perspectives of families must be amplified to ensure new employment interventions are socially valid. At the same time, we recognized that families may hold views that diverge from what we—or others in the field—think is most salient or pressing. Throughout the coding process, we strived to temper our own views and foreground the voices of families.

We used thematic analysis to address our research questions (Patton, 2015). Our practical goal was to compile a comprehensive listing of barriers that might hinder access to integrated employment, while also identifying those categories of barriers that garnered the most emphasis. Data analysis occurred in multiple stages. First, team members conducted an initial reading of each transcript as they listened to the audio. We took notes regarding the array of barriers named by participants throughout each interview. We then compiled a first full list of each distinct barrier from across all 60 participants. We developed definitions for each barrier, organized them thematically into tentative categories after discussion, and created our initial coding framework.

Next, two sets of team members independently coded all transcripts, splitting them in

half. In pairs, but independently, we read each transcript closely and assigned an initial code to relevant segments of each transcript (e.g., short phrases to multiple sentences). We utilized codes from the initial framework or generated new codes when necessary. We then met in pairs to compare and discuss our coding. This process involved working line-by-line through each transcript to address each code and definition. Through these discussions, we resolved discrepancies and sharpened our definitions. We also met as a whole team to revise the coding framework as new codes were defined and added. We organized our codes into categories and sub-categories based on key similarities. After discussing our coding and findings multiple times, we finalized the coding framework and reviewed every transcript again to verify that all codes were correctly assigned and honored the sentiment of the participant.

We used Dedoose as a tool for organizing our coding and summarizing our findings. To characterize the overall weight participants attributed to each barrier, we examined the total number of references to each barrier, calculated the proportion of participants who raised each barrier, and considered the substance of coded quotes and the tone with which they were discussed. Thus, we avoided relying solely on code counts or length.

We took several steps to strengthen the trustworthiness of our findings (Brantlinger et al., 2005). First, we adopted recruitment strategies and inclusion criteria to ensure each participant had first-hand experiences related to the pursuit and support of integrated employment. Second, we kept a detailed audit trail of our interview and analytic procedures. Third, we used a collaborative approach to coding that combined investigator triangulation and consensus building as a check on any individual biases we may have brought to this work. Fourth, we incorporated member checking by sharing a summary of themes back with each participant via email, while asking them to share anything they felt was missing or incorrect from the summary document. We undertook this step to ensure we accurately represented the barriers they identified and did

not overlook any key issues they raised.

### Findings

The barriers to integrated employment identified by participants fell within six primary areas. Figure 1 presents each of these themes and the array of associated barriers. The attention given to each barrier is evident both in the percentage of participants who raised each barrier, as well as the total number of times each barrier was discussed. In the following sections, we present brief and extended quotes as a way of illustrating barriers (shown in *italics*) falling within each theme. The race/ethnicity of parents (AI = American Indian, AA = Asian American, B = Black, H = Hispanic/Latinx, M = Multiple, W = White,) and age and disability (ID = intellectual disability, A = autism, ID+A = both) of their family member is indicated in parentheses (e.g., X, 23, ID).

#### Individual Factors

Participants (72%) identified 16 barriers that they attributed to the abilities, attitudes, or skills of their family members with IDD.

##### *Abilities*

Half of participants felt the limited abilities of their family member in one or more areas hindered their employment prospects. Although some participants recognized that certain supports could help mitigate these challenges, others struggled to envision work opportunities that matched well to their family members' abilities. The presence of *cognitive impairments* was said to make understanding directions or processing information—two key workplace requirements—much more difficult. For example, one mother felt certain that “a job where he’d have to read a lot of directions” would not be appropriate for her son (W, 23, ID). Another parent said of her daughter (W, 38, ID), “She understands directions, but it has to be simple. One step at a time.” *Communication challenges* impacting verbal speech were also raised repeatedly. One

mother illustrated how this constrained her son's (W, 25, A) job opportunities:

He needs to be in a very task-oriented job and not anything that would require any kind of customer service, just with his verbal communication limitations and intellectual communication limitations.

*Physical difficulties* related to mobility and dexterity were also said to limit work options.

One sibling questioned the longevity of her sister's (W, 58, ID) current position, saying:

I think the issue I'm really stating there is the aging issue. What does a career path through the ages look like? I'm concerned, even now at 58, how much longer she'll be able to do the kind of physical work she's doing.

Such difficulties sometimes impacted work *endurance*. Thinking about her son (W, 19, A), one mother stated, "We would love them to have a full-time job, but I don't think they're physically or mentally able to handle that." Another mother felt the same was true for her son (W, 20, A), "More than four hours a time period is too much for him. You're going to lose him after four hours." Finally, *sensory challenges*, such as aversion to certain noise or light levels, were raised.

### ***Skills***

Half of participants also attributed employment difficulties to the current skills of their family member. Unlike abilities, these challenges could be addressed through instruction. Some skills were considered foundational to obtaining a job (i.e., *driving skills, personal care skills, job search skills*), while others could be taught or supported on the job (i.e., *self-management skills, social skills, initiative skills, financial skills*). Some of these skills, however, were emphasized more than others. *Social skills* were a widespread concern. As one mother shared about her son (W, 22, A), "Being on the spectrum...the actual skill of doing the job is never going to be the problem. It is navigating all of the hidden agendas and the water cooler talk." *Self-management skills* also impacted independence on the job ("Well, she has difficulty with time management. That's why it's good for her to have a job coach. She has to be prompted." AA, 40, A). The inability of many family members to drive on their own to work was a frequent

point of discussion among participants. Maintaining a job would require having “assistance driving to and from [work]” (W, 20, A) or living “someplace that’s close enough to walk where he works or live in a part of town where there would be public transportation” (W, 20, ID).

### ***Mindsets***

A quarter of participants felt that certain attitudes or perceptions of their family members with IDD made employment less likely. Some participants struggled to motivate family members who had *limited interest* in employment. For example, one mother shared, “My daughter (W, 34, ID) is not motivated to work. That is not what she wants to do.” Others found it hard to accommodate their family member’s narrow preferences or strong resistance to trying certain occupations. As one mother shared about her son (W, 25, A), he “doesn’t want to work in the food industry, things like that, and there’s a lot of jobs in that industry. So, if he doesn’t want to work there, the job pool decreases.” Several parents felt their family member lacked a clear *understanding of employment* due to the severity of their disability (“She doesn’t really understand employment.” W, 17, ID). For example, one mother described her son’s (W, 20, A) resistance to continuing work after receiving his first few paychecks, “He started giving me a hard time saying he didn’t want to go anymore—why did he have to go because he already had money.” Three participants described their family member’s *resistance to support* related to work. Finally, one mother described her son’s (W, 22, A) *poor self-assessment*, saying, “I’ve also seen him underestimate his ability—very black and white thinking.”

### **Family Factors**

Participants (65%) identified 12 distinct barriers related to the capacity or commitment of their family to support integrated employment. These barriers fell within the areas of knowledge, mindsets, logistical issues, and supports.

### ***Knowledge***

Nearly half (45%) of participants addressed how their limited knowledge of certain topics impacted their pursuit of employment. Specifically, numerous participants were frustrated by their limited *knowledge of services* that could enable their family member to work in the community. As one grandparent (W, 23, ID) shared, “We need more information on what we can do. How can I help him? What is out there?” Some participants explained that they never received needed information. For example, one father shared how alone he felt when preparing his son (H, 19, ID) for employment, “In my circle of friends, we are the only family with somebody with disabilities.” A mother whose daughter (W, 21, ID) recently graduated high school likewise lamented, “I think that’s why so many... adults with intellectual disabilities don’t work... nobody knows what to do once you get out.” Other participants explained that the information they received was hard to understand, came too late (“I think there’s a lot of resources out there... sometimes we find out about them too late or we don’t even know about them at all” W, 21, ID) or was just “too broad” (W, 31, ID+A). One highly educated mother of a 21-year-old daughter (W, ID) expressed a sentiment held by so many others we interviewed, “I’ll be honest, sometimes it feels like a full-time job trying to get in touch with resources and figuring out what we can do.”

The area of *navigating government benefits* was also said to be fraught with difficulties. Although many adults with IDD rely on supplemental security income (SSI) or social security disability insurance (SSDI), 14 participants were uncertain of how to obtain or retain these much-needed resources. Two quotes summed up the experiences of many other families related to working with the Social Security Administration. One mother of a young adult son (W, 20, ID) said, “I feel like I’m reasonably intelligent and it is the most complicated and convoluted thing I have ever seen.” Another mother of an older son (W, 29, A) described, “It’s just scary, because I feel like I’m pretty well educated. But I’m so lost when it comes to this stuff!” Two

final knowledge concerns, each raised by two parents, centered on *disability disclosure* and *legal authority*. Both parents were uncertain how and when to reveal disability information during the employment process. Likewise, two parents were uncertain about whether having conservatorship would make working closely with employers more difficult.

### ***Mindsets***

Almost half (42%) of participants described how the views and beliefs of families could hinder employment. Many families referenced their own *expectations* as a potential barrier. In some cases, this mindset was attributed to never having seen examples of success among individuals who resembled their family members. Other times, it related to the intensity of their child's support needs ("Honestly, I can't see that happening," W, 21, ID). One mother asserted that a lack of creative thinking and high expectations was quite common:

It's not just businesses, sometimes it's us parents, too! Our perception of what our kids can accomplished needs to be changed. This is all we know...So, I think helping them to expect more and see those abilities and giftings—and push the envelope a little bit—that's really the only way things are going to change.

She then added, "I notoriously underestimate my son" (W, 29, A). One Spanish-speaking mother, whose son (H, 32, ID) had not worked since high school, said, "If he doesn't communicate or doesn't understand what they tell him, well, I don't think he's going to do anything at all."

Eight participants raised *concerns about benefits* that could be lost if their family member with IDD found employment. Their desire to protect these government benefits was sometimes based on misunderstandings or myths surrounding SSI/SSDI. However, one older mother whose daughter (W, 46, ID) was currently working noted, "I've known more than one person who would not consider letting their child work because of [fear of] losing their benefits."

Nine participants also mentioned their *safety concerns* related to integrated employment.

Although not always considered a “deal breaker,” they remained apprehensive about what is possible. Some parents worried their child could be taken advantage of due to their trusting nature and difficulties with discernment. As one older mother explained, “My daughter (AA, 40, A) has been taken advantage of many times and that’s why I don’t trust her with anybody.” A mother whose daughter (B, 24, ID) was currently employed said she was still “afraid somebody’s gonna lead her wrong and she’s going to get in trouble for something that she had no understanding [of].” One mother of a transition-age son (W, 19, ID) expressed that she was cautiously optimistic this concern could be assuaged with the right job:

For my son, I think it's going to be finding that perfect, that sweet spot that allows him to use his cool planning skills and ideas, and his desire to be around people with his safety, environmental hazard stuff.

### ***Logistics***

Two family factors related to logistics. Eight participants noted times when *schedule mismatches* made supporting their family member’s work schedule quite difficult. Part-time positions—or those with erratic schedules—make it difficult for caregivers to work full-time and still provide transportation and supervision. As one mother of a young adult son (W, 25, A) explained, “It has changed my schedule, but I have a flexible schedule. But his schedule dictates mine, it's not the other way around...So it greatly impacts me.”

Similarly, a few parents mentioned that *competing priorities* affected their availability to support their child’s work aspirations. One mother addressed what she perceived as the expected trade-off for her son (W, 29, A), “Where do I go from here now? Do I have to stop my job and stop work in order to find him a part-time job and step back in?” Likewise, another parent explained her financial dilemma related to finding her son (W, 20, A) a job, “I’m a single mother, so I don’t have the funds to really be leaving work to go pick him up from work, driving him to and from work, that kind of thing...There’s a ton of barriers. It’s really hard.”



### *Supports*

The absence of needed supports was raised by 12% of participants. Five participants mentioned drawing upon their *personal networks* in pursuit of employment. They recognized the potential power of these relationships, but were unsure where to begin. One sister described this challenge in relation to supporting her sibling (W, 58, ID), “I do think a big part of the journey—and the difficulty—is figuring out where to start and who to talk to.” Similarly, a mother described this same frustration when pursuing work for her transition-age son (W, 19, A):

I feel like if I personally knew people who are hiring or if I knew small business owners, I think I'd already be on top of that, but I don't. I don't have those connections, but I feel like I'd be the one and my husband would do it too. We would be the ones doing all the connecting and connecting the dots.

Less common, but still impactful, was the *absence of a support team*. Two participants shared that the employment outcomes of their family member depended almost entirely on them alone. One sibling, who recently became the main support for her sister (W, 58, ID), considered it to be “a tremendous responsibility and task.” She continued, “Without me, I do think she would be, for a season at least, fairly lost. She's getting better connected in the community, but she would not be able to go out and find a job by herself.”

The absence of support contributed to *parent fatigue*. One father of an employed son (W, 28, ID) said he had encountered numerous parents that are “just overwhelmed and they feel, a lot of parents that I talk to just feel totally inadequate.” A mother described the moment “when I finally gave up” after being told by the service system that she should pursue social opportunities instead of employment opportunities for her son (W, 20, A). Finally, a mother of a transition-age son (W, 20, ID) simply stated, “Parents such as myself, they just get worn out.”

### **Service System Factors**

Participants (72%) identified 14 barriers related to access to or quality of services that

would enable employment. They attributed these barriers to inadequacies of the service system.

### *Access to Services*

Close to half of participants (47%) said they struggled to access adult services needed to support their family member's employment pursuits. For some parents, the *lack of job coaching* left their family members without the support needed to be successful in the workplace. For example, one mother recounted the unsuccessful work experience of her son (W, 22, A) who lacked this on-the-job support, "Things that you and I think are so easy and just we know, he didn't know. That's the coaching he needs." When asked which barrier was the most challenging for her teenage son (W, 17, ID+A), another mother replied, "The job coaching portion.... He's not going to take direction from me."

Over and over, the pathway to attaining need services was described as onerous and fraught with difficulty. Some participants described the considerable difficulties they had *applying for services*. One mother of a transition-age son (W, 19, A) described being left on her own to figure out how to access needed services, "It's almost like you got to have to hunt to find the resources." Others described the limited *reach of services*, particularly for rural families ("They had to outsource (a job coach) over a 50-mile radius." W, 27, A). Even if the application process were successful, families held out little hope that services would be available. However, this absence of services was also raised in urban communities. One mother of a young adult son (B, 25, A) explained, "There's not enough providers, period. No matter where you live!" Participants also described extended windows of *waiting for services*, sometimes spanning multiple years. Exasperated, one mother of a transition-age son (W, 20, A) exclaimed, "We've been on the waiting list for two years. Two years!" For an older father whose daughter (W, 60, ID) needed vocational rehabilitation services to work, the delay was especially difficult:

I'm not sure what the problems leading to the inefficiencies are, but it took two years for

VR to finally get an agency together and the agency for her to get a job...I know what the issues are for some of the case workers, so pressuring them doesn't necessarily get you anywhere.

Finally, some families felt that the *clarity of services* were too perplexing to easily understand.

For a mother whose son (W, 29, A) was eventually able to obtain work, knowing who could help was so hard to discern: "It's just scary. I feel like I'm pretty well-educated, but I'm so lost when it comes to this stuff...I feel like you're just going down the rat hole of never really having a secure future." Another mother whose daughter (W, 22, ID+A) recently graduated agreed, "That is just a spiderweb of not knowing what to do, where to go, who to call."

### ***Quality of Services***

Even when employment-related services could be obtained, participants (55%) encountered major limitations with their quality. Multiple aspects of service quality were raised throughout the interviews. Participants highlighted the *insufficiency of services* in meeting all of their family member's pressing employment needs. Speaking about her recently employed son (W, 20, ID), one mother still noted, "The amount of resources that are available seem pretty limited." In some cases, the funding allocated to employment supports was considered too meager. In other cases, staff were said to lack the preparation needed to promote employment. The mother of an older daughter (AA, 40, A) who remained unemployed explained, "She's left hanging. We've been waiting for a job for the past 3 years now...she's really getting very frustrated." Others raised concerns about the *reliability of services* and degree to which they were dependable once obtained. An older mother described her frustrations here:

Our daughter (W, 31, ID+A) has been thrown out of the program. And we're like, why? No one knows and you have to appeal. Then all these appeals get denied. And then you find out she's miraculously back on. No one told you! We've done that like three times, so that's a big issue.

For another mother whose son (W, 25, A) was excited to find a job, dependability was a concern:

Whatever was communicated, it wasn't being translated. I found out later that somebody with their agency misfiled everything or didn't even put stuff in his file. I mean, all the stuff that could happen, it happened. It was probably six, seven months before he actually got somebody that knew what they were doing and actually helped him look for a job.

The short-term *duration of services* was also considered by some participants to be insufficient to meet the needs of family members whose support needs were more intensive. Speaking about vocational rehabilitation services accessed by her son (W, 22, A), a mother shared, “Their job, it seems to me, is get a job and they're done. The follow-up that they have is not really follow-up. They're supposed to follow-up, but they didn't.” Similarly, another mother described the unexpected drop-off of workplace support for her daughter’s (AA, 40, A), “They had a job coach for her, but the job coach didn't stay very long...She was kind of left there on her own.” Other participants spoke of a mismatch when it came to the *priorities of services*. Families held different expectations that agencies regarding the amount (e.g., full- versus part-time), setting (e.g., integrated versus sheltered), or type of work they would support. One father shared, “We are told that we have to think [a certain] way in order for our child (H, 21, ID) to receive any assistance from any agency.”

Other concerns related to service quality were mentioned less often, but are still salient. These included the *lack of personal support* (“They need to not push the parent out of the picture!” B, 25, A), *fragmented services* (“We've tried so many different programs, so many different suggestions [from] people and we've got nowhere, but it's because there's not been an organized effort to meet the needs of everybody.” W, 38, ID), *poor collaboration* (“There's not anybody that I have found that absolutely understands the entire umbrella perspective.” W, 22, A), and *service system attitudes* (“People feel like your child is a burden and not valuable” W, 21, ID). All of these various barriers led many participants to question the overall *helpfulness of services*. Even when employment services were obtained, there was little confidence that those

services would make a substantial difference for their family member.

### **School Factors**

Participants (17%) identified three primary barriers to employment related to the roles of secondary schools. This modest level of attention to educational concerns may be because more than three quarters of family members had already graduated and exited transition services. Five participants indicated that schools provided *insufficient instruction* related to employment preparation. Despite clear mandates for transition services, these parents described high-quality instruction as unavailable or uneven. One mother felt she had to take things into her own hands, “You have to come in and basically train the school. That's what I had to do in my daughter's (B, 16, A) high school. I got there, there was no curriculum.” Likewise, a parent who was utterly dismayed by her son's (H, 32, ID) experiences back in school, had simply wished “for them to teach him to do *something*. Because, honestly, at school, they didn't teach him to do anything. I think he just went to school to sit there.” Other parents, like the mother of transition-age daughter (H, 16, A), felt that instruction should be more rigorous and start at an earlier age “so they have the same chance as a typical child.” In short, these parents felt that the schools “are not preparing our students.”

Employment opportunities could also be constrained by *educator expectations*. Four parents said their child's teachers could not envision integrated employment as a possibility. One mother of a transition-age daughter (W, 21, ID) suggested that “there is not a lot of expectation for what happens after high school.” Some parents felt that teachers held very narrow views of the skills students could learn and the type of work they could attain. For example, one mother whose son with severe disabilities (B, 23, ID) had recently graduated said that his school “just wants to teach them what they think the kids are limited to,” without pushing beyond preconceived boundaries. Another mother bemoaned the low expectations she observed at her

daughter's (W, 46, ID) school: "When she finished there, the only thing that she qualified to do was food services."

*Poor communication* was also said to characterize the interactions between some schools and families. The absence of effective information exchange contributed, in part, to the limited knowledge about employment options and services among some parents. One mother voiced her utter frustration with the absence of open communication at her daughter's (W, 21, ID) school:

No one had walked us through anything before. Even in the school system. I think to some extent people don't want to make you feel bad, so they don't tell you some opportunities or some things. Because the truth is, she's intellectually disabled, so let's call the fact and then give me some resources.

### **Workplace Factors**

Participants (68%) identified 13 workplace barriers related to the application process, mindsets, and workplace supports.

### ***Application Process***

Obtaining employment is contingent on successfully navigating the application process, which was identified as a challenge by small number of participants (17%). Yet, the process of applying was sometimes hindered by issues of *application accessibility*. Several parents felt the traditional application process was designed for neurotypical people, but not those with disabilities ("He can't go to a normal interview anywhere and have success." W, 20, A). Their family members were said to either need assistance completing applications ("He decided to fill out [the application] out while he was there. Of course, he called me up while he's filling it out to have help understanding the questions." W, 22, ID+A) or interviews ("He needs help; probably somebody going to the interview with him. I think he needs that support." W, 25, A). In larger companies, participants also shared examples of *administrative hoops* that delayed or deterred hiring. In some larger chain companies, corporate approval was required before hiring

someone with extensive support needs, which created a very long wait period after the interview process (“The manager had to wait on corporate.” W, 27, A). Furthermore, corporate concerns about liability often stalled hiring. One mother described the challenge of getting her son (W, 19, ID) hired, “We had a fabulous manager that wanted to hire for four years now and corporate—the nationwide corporation—said it was a liability and it wasn’t going to happen.”

### ***Mindsets***

Nearly half (53%) participants described attitudes or expectations within workplaces that could impact employment. *Employer willingness* to hire adults with IDD was the most prominent of these barriers (“We don’t know who’s willing to hire people with disabilities in our own community.” W, 25, A). Reflecting on the process of helping her daughter (W, 21, ID+A) find a job, one mother shared:

I think one of the harder parts of it overall is still the employer side of it—having employers that are willing to hire them, employers that are willing to keep that communication open. I wish there was something—somewhere—that would pool those [employers] together just to have options and know that there’s a place to go that can be supportive for us to work with.

This willingness was often tied to *employer expectations* regarding what people with IDD can contribute. As one father (W, 60, ID) shared, “People’s perceptions and understandings of what an intellectual disability can do are pretty limited.” Employers were said to have narrow—and often low—views of the types of roles and responsibilities people with IDD could take on. Other participants addressed the importance of *employer readiness*, or the degree to which an employer felt prepared to hire and support an employee with IDD. Parents did not want to pursue a position without being confident that an employer really understood the needed commitment. One mother of a transition-age son (W, 20, A) explained, “I can’t just take him on any interview just anywhere. It’s going to have to be somebody that understands his disability.” Another parent whose son (W, 22, A) had just graduated, affirmed this point, “If we don’t get some workplace

readiness for the employer, it's not going to work."

Barriers related to mindset were not just limited to hiring managers. A number of participants discussed the detrimental impact of *co-worker attitudes*. They shared stories of co-workers who treated their family member "like he was a child" (B, 25, A), lacked "understanding of her abilities and her strengths and weaknesses" (W, 32, ID), and assumed "his discrepancies are having a bad attitude or him being lazy" (W, 26, A). One mother voiced her worries about how well future co-workers might treat her daughter (B, 19, ID):

I think having a receptive work group is probably the most challenging. Having folks who can understand, support, and respond to these young people in their environment—I definitely think that is the biggest barrier.

### ***Workplace Supports***

Many participants (32%) emphasized how key aspects of a work environment could impact their family member's success. One overarching concern related to the pervasiveness of *unsupportive environments*. One mother described her son's (W, 22, A) workplace in disappointing ways, "The surrounding environment was not supportive. And it didn't matter how good he was at the job and those things—for someone on the autism spectrum, that workplace environment support has to be there." The absence of needed support was sometimes described as the norm; other times, it resulted from sudden changes in management. Another mother experienced this with her son's (W, 39, ID) job, "You could have the best situation and then they change the manager, the people, the community. And everything changes!"

Specific supports were also noted by their absence. For example, three parents discussed the *inadequacy of training*. One mother shared that her son (W, 27, A) had experienced the loss of several jobs due to lack of training, saying "Another barrier is when they judge them by their mistakes and don't train them." *Inaccessible facilities* were also mentioned, but only by parents whose family members had physical limitations ("There's so many things that need to be



considered that are supposed to be and that are not always.” W, 23, ID). *Employer collaborations* with outside agencies were also said to be limited. For example, one mother explained that her son’s immediate manager was “not interested at all” in meeting with her son’s (W, 22, A) job coach every other month in order ensure his long-term success.

Several concerns in this area related to workplace variations (or lack thereof) over time. *Fluctuating tasks* were said to be difficult for some family members (“Her supervisor gave her a different job every night.” W, 46, ID). Likewise, *variable scheduling* was described by participants as “very inconvenient” (W, 46, ID) and challenging to “figure out all the logistics and details” quickly (W, 58, ID). In contrast, the limited *opportunities for growth* meant that some participants could not envision their family member’s job lasting long-term. Addressing the seemingly stagnant responsibilities of her sister (W, 58, ID), one sibling emphasized “We all want a career path. She can vacuum...[but] is there anything else she can do in that job setting?”

### **Community Factors**

Participants (55%) identified seven community-level barriers related to transportation, community attitudes, and employment outlook.

#### ***Transportation***

Transportation was by far the most-mentioned barrier, having been raised in some way by 55% of participants. Reference to its importance and impact punctuated the conversations: “transportation is a big barrier” (H, 21, ID), “transportation is huge” (W, 19, ID), “transportation is big,” “transportation is very important” (W, 22, A), “transportation, it’s a whole thing” (W, 29, A), “the biggest challenge is transportation” (W, 28, ID), and “it’s a deal breaker” (W, 39, ID). Five distinct dimensions of the transportation challenge were named. Concerns about *transportation availability* were most prominent. The absence of any public transportation marked many communities, particularly rural counties (e.g., “there’s no bus routes around here”

W, 20, A; “We do not have Lyft or Uber available” W, 27, A). Amidst this absence, families often lacked viable alternatives. As one mother explained, “I can’t leave [my job], drive, pick him (W, 20, A) up, take him back. There’s *no* way.” Even when available, *transportation reliability* was problematic. Many participants shared stories of missed appointments (“There were times they didn’t show up.” W, 22, A), erratic arrivals (“You never know for sure when they are going to show up!” W, 34, ID), and late pickups (“They may be half an hour late or two hours early or not show up.” W, 31, ID+A). This unpredictability directly impacted work success and became a source of considerable stress. One father illustrated the challenge of simply getting his son (H, 26, A) to work each day:

[Transportation] is a thing we almost have some kind of intervention on every week. Because he’ll call me and it is a half hour past due and they still haven’t pick him up. And then I go and pick [him] up and that’s another 20 minutes. And the clock’s ticking and getting close to his clock-in time.

Worries about *transportation safety* were raised when drivers were unknown to families. One mother shared her fears for her son (W, 22, ID+A), “I did have some concerns about his safety when he rode the bus to [urban city] because I felt like I was throwing him to the wolves.” The father agreed, “He (W, 28, ID) wouldn’t recognize if somebody was threatening on a bus, especially if they were savvy or if they’re going to take advantage of him.” *Transportation cost* was also a barrier for some individuals and families. Even with reduced rates available, ride share and other transportation programs can capture a substantial portion of a persons’ income. One mother illustrated, “We used a lot of Lyft. He (W, 22, A) used a lot of his income—\$600 a month out-of-pocket for his transportation.” Finally, *transportation ease* was another barrier identified by participants. Using apps, making bus transfers, and navigating to work from a distant stop were all named as potential difficulties for their family members.

### ***Mindsets***

Some participants (22%) described how *community attitudes* could diminish the employment prospects of their family members. Prevailing views about whether people with IDD can make valued contributions in the workplace were a source of considerable concern. As one mother of a transition-age daughter (H, 16, A) explained, “It’s a constant fight with society.” Fears about how their family member would be treated in the workplace led some parents to question whether pursuing work was really the right path for their daughter or son. One grandfather recounted the many ways people underestimated his grandson (W, 23, ID):

It’s a lot of prejudices and not respecting the person as a person and what they are capable of doing. People are capable of doing a lot if they’re challenged! I believe that. And if they’re respected and praised—and not punished—they function well.

Likewise, a mother whose son (W, 31, ID+A) was not working called for change:

So, I think so much depends on the community’s perceptions of our kids. And I think that is a big puzzle piece that we are missing. As far as helping them to see our children’s abilities instead of the disability.

### ***Employment Outlook***

Multiple participants (13%) were discouraged by the *lack of job opportunities* in their local community. This limited availability was attributed to multiple factors. For example, participants living in rural areas described the paucity of positions for anyone in their county (“I just don’t know if it’s going to be possible in our county.” W, 24, A). One father from a small community noted that “the possibility of opportunities is nil to none” for his daughter (W, 38, ID). As a result, some participants, like this mother of a transition-age son (W, 20, A), felt they had no other choice but to explore non-work alternatives:

It might just be what’s offered in our area, and maybe people’s perceptions of people that are different. Most of all the people I know do not have jobs. The parents are very involved, and we keep them all together, and we do volunteer stuff. But I don’t know any that have actual jobs.

## **Discussion**

National disability policy has consistently connected employment to human flourishing (e.g., Americans with Disabilities Act of 1990; Workforce Innovation and Opportunity Act of 2014). Indeed, a paid job in the community can go a long way toward advancing the core outcomes of “equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities” (Turnbull et al., 2003). We sought to identify the constellation of factors that coalesce to hinder access to integrated employment and the benefits work can bring. Our interviews with diverse families extend the literature in several ways.

First, we were struck by the sheer number of different barriers generated by these parents and caregivers. Indeed, there was a certain intensity with which these myriad challenges were discussed and very little pause between the end of our first question on this topic and the long flow of responses. It was clear that the pursuit of employment had been—and continues to be—a struggle for many of the families with whom we spoke. Collectively, they named nearly 70 different barriers, twice the number of different concerns generated in two prior studies of families by Carter and colleagues (2018;  $n = 35$ ) and Francis and colleagues (2018;  $n = 27$ ). All three studies share many concerns in common, such as skill limitations, safety concerns, transportation access, prevailing attitudes, the availability of services, and the adequacy of supports. The recurrence of these same difficulties across people and time is a reminder that many pressing barriers still endure. At the same time, participants in our study focused on some distinct issues (e.g., the quality of transition services; the mindsets of parents; the application process) or brought added nuance to widely recognized barriers (e.g., transportation, service quality). The culminating map of prevailing barriers—with its breadth and detail—pinpoints the many individual factors that may still be maintaining disappointing employment rates nationally. Despite decades of developing new solutions, longstanding barriers remain present and pressing.

Second, responding to this varied collection of challenges will likely require a multi-

faceted response. Our analyses identified six primary areas to which participants attributed these barriers: individuals with disabilities, families, service systems, schools, workplaces, and communities. In actuality, many of these barriers could have emerged from multiple places. For example, a young adult's skill-related limitations could result from poor instruction during school, low expectations among their family members, and/or limited opportunities to practice skills in the workplace. Therefore, comprehensive employment interventions may require providing individuals with strong instruction, providing support and encouragement to families, strengthening transition programming in schools, strengthening the availability and quality of employment services, equipping employers with information and ideas, and raising awareness and opportunities within communities (Carter et al., 2016; Wehman et al., 2021). As evidenced in other studies focused on changing the local employment landscape (e.g., see Carter & Bumble, 2018), communities must think creatively about how all six areas might be addressed locally and in tandem. Indeed, the intersecting nature of these numerous barriers highlight the need for much more comprehensive solutions and strategies than are currently advocated within the literature (e.g., Schutz & Carter, 2022).

Third, some of these barriers to integrated employment received far more emphasis than did others. For example, the absence of viable transportation was considered especially problematic by more than half of parents. This perennial barrier, which has also been raised by adults with varied disabilities (e.g., Sabella & Bezyak, 2019), also impacts other aspects of community participation. Likewise, the attitudes and expectations of educators, employers, providers, parents, and the general community were all raised as prominent limiting factors. Addressing prevailing mindsets requires a long-haul investment that combines awareness efforts, education, and contact into comprehensive interventions (Seewooruttun & Scior, 2014). Finally, access to employment services was said to be especially fraught with difficulties. Many parents

were unsure of how to find relevant services, unsuccessful in obtaining needed services, or disappointed with the services they ultimately received. For individuals who need long-term supports in the workplace, the uneven quality of employment services needs to be remedied.

Fourth, geography and disability may amplify the impact of a number of these barriers. For example, some challenges seemed to be especially pronounced for families living in rural communities (cf., Adams et al., 2019). The absence of public transportation options, diminished job opportunities for any resident, and the limited number of available service providers all complicated employment pursuits of families living far from large cities. This finding is consistent with what the literature has affirmed regarding the complexities of addressing employment in rural communities (e.g., Rowe et al., 2020). Likewise, securing work for family members with more intensive support needs seemed especially challenging. Participants whose family members had a cognitive impairment tended to raise heightened concerns about the skills and abilities of their family members and noted the difficulties finding adequate support in the workplace.

### **Limitations**

Several limitations place parameters on these findings. First, we focused narrowly on the perspectives of just one family representative (i.e., mostly parents), to the omission of spouses or other caregivers. Given limited resources, we wanted to hear the experiences of more families, rather than speaking to multiple people within fewer families. The variations in views reflected across all study participants may also be evident within family units (e.g., mothers, fathers, and siblings may see things differently). Future studies should also ask family members with IDD to also share their thoughts regarding employment challenges. Second, we strove to recruit a sample that was diverse in terms of race/ethnicity, geographic local (within our state) and education level. Although we recruited enough diversity to incorporate the perspectives of many

different groups into our analyses, there may not have been enough variability in our sample to dive deeply into the experience of families from marginalized backgrounds. Future studies focused directly on these families may yield additional barriers or different emphases. Third, we relied on participant descriptions of their family members with IDD. In our reluctance to ask parents to complete additional formal assessments, we could only rely on disability labels and perceived support needs when analyzing our findings. Fourth, all of the participants were from one southern state; the extent to which the findings are generalizable to other states with varying supports and service systems is uncertain. Fifth,

### **Implications for Practice**

Our findings underscore the value of asking parents and other caregivers about their experiences pursuing employment and the challenges they encounter along the way. Although there were many barriers that received broad affirmation, no two parents described their challenges in precisely the same way. Each described a different combination of roadblocks or experienced common barriers in somewhat different ways. Special educators, employment providers, and other professionals should ask about the things that parents worry will stand in the way of work for their family members with IDD, along with their ideas for addressing those concerns. As with most other areas of recommended service delivery, presumptions should be replaced with good questions.

As common themes arise from conversations with multiple families, local communities should work in concert to address the most pervasive or pressing barriers. The constellation of concerns reflected in Figure 1 require a comprehensive and coordinated response. Challenges related to the practices and postures of schools, workplaces, service systems, and communities were raised throughout all the interviews. Likewise, the perceived capacities and commitments of individuals with IDD and their families were also named numerous times. The intersecting

nature of these myriad areas suggests that addressing just one in the absence of the others is unlikely to result in noticeable improvements in the local employment landscape. Strong community-level collaborations are needed that cut across programs (e.g., education, vocational rehabilitation, developmental disability services) and engage people from outside of the formal service system (e.g., employers, civic leaders, community non-profits). This could involve establishing a local core team that serves as the backbone for community wide change efforts. It could also entail hosting community conversation events as a way of identifying and engaging local partners across sectors who can help resolve relevant barriers (e.g., Carter & Bumble, 2018).

Families can also consider ways of addressing barriers that fall within their own sphere of influence. For example, parents who struggle to envision employment for their daughter or son might meet with other families who have successfully navigated this journey and can share their stories or advice. When their children would benefit from developing skills or attitudes that could promote employment and enhance their self-determination, parents can connect them with instructional opportunities, hands-on experiences, or mentorship. When parents who are unfamiliar with employment services and supports for individuals with IDD, they can attend local workshops, join parent networks, access resources from state agencies and local providers, or seek out meetings. To support families, local disability organizations could consider facilitating research-based programs—such as *FEAT* (Francis et al., 2014), *ASSIST* (Taylor et al., 2021), or *Transitioning Together* (DaWalt et al., 2018)—that equip families with information, advocacy skills, and encouragement in these areas.

Creative, effective solutions are still needed to address longstanding barriers to employment for individuals with IDD. Parents and other family members remain critical partners in this important pursuit of meaningful work. Their perspectives on the most salient and



substantial barriers to employment should inform the efforts of schools, agencies, and providers charged with improving outcomes for youth and adults with disabilities. It should also inform the efforts of employers to build a more diverse workforce. We hope the findings from this qualitative study will spur new thinking about how best to design employment services and supports in ways that obviate and overcome these barriers.

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Table 1

*Demographic of Participants and Their Family Members with IDD*

Demographic variable	Participants		Family members	
	<i>n</i>	%	<i>n</i>	%
Relationship to family member with IDD				
Parent	55	91.7	-	-
Grandparent	1	1.7	-	-
Sibling	4	6.7	-	-
Age				
10-19	0	0	12	20.0
20-29	1	1.7	34	56.7
30-39	3	5.0	9	15.0
40-49	10	16.7	2	3.3
50-59	28	46.7	2	3.3
60-69	11	18.3	1	1.7
70-79	6	10.0	0	0
80-89	1	1.7	0	0
Gender				
Female	49	81.7	22	36.7
Male	11	18.3	38	63.3
Race/ethnicity				
American Indian/Alaskan	1	1.7	-	-
Asian American	1	1.7	-	-
Black	11	18.3	-	-
Hawaiian/Other Pacific Islander	0	0	-	-
Hispanic/Latinx	7	11.7	-	-
White (Not Hispanic)	41	68.3	-	-
Highest level of education				
High school or less	7	12.3	-	-
Some college	8	14.0	-	-
2-year degree/Associate's degree	8	14.0	-	-
4-year degree/Bachelor's degree	17	29.8	-	-
Master's degree	13	22.8	-	-
Doctoral degree	4	7.1	-	-
Community type				
Rural	10	16.7	-	-
Suburban	22	36.7	-	-
Urban	28	46.7	-	-

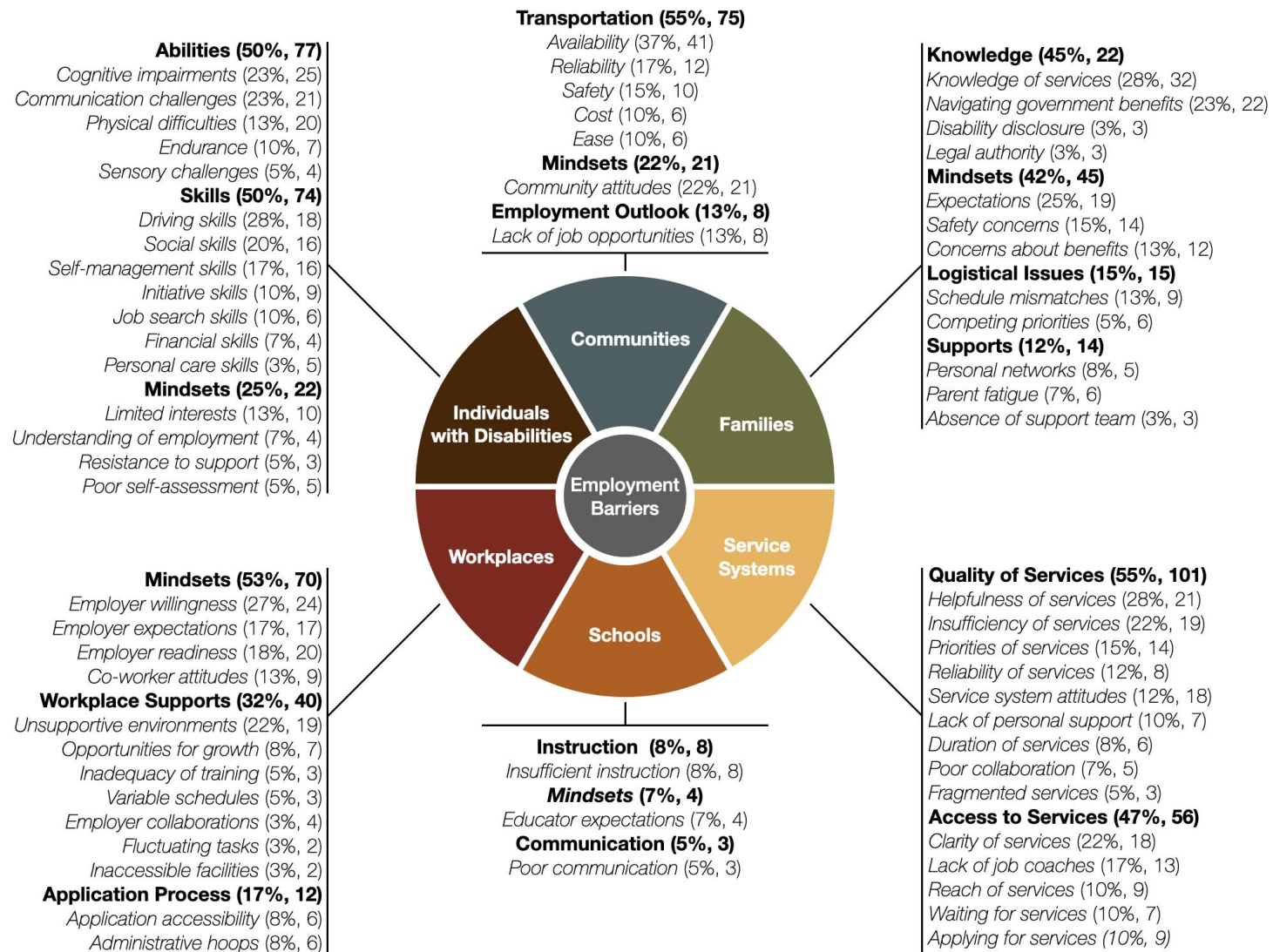


Figure 1. Barriers to employment organized by category and emphasis. Percentages refer to proportion of participants raising each barrier. Frequency refer to the total number of times each barrier was raised.