Intellectual and Developmental Disabilities

“It’s So Tough!”: Barriers to Respite Care for Families of Children with Disabilities

--Manuscript Draft--

Manuscript Number:	IDD-D-24-00079R1
Article Type:	Research
Keywords:	respite care; disabilities; children; families; caregivers
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Manuscript Region of Origin:	UNITED STATES
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Abstract

Although respite care can have a profound impact on the well-being of families, most parents of children with disabilities struggle to access these scarce services. The purpose of this qualitative study was to map the breadth of barriers families encounter in their pursuit of respite care. We interviewed 31 parents of children and youth with intellectual and developmental disabilities (IDD) about their experiences and the challenges they navigated. Fifteen key barriers emerged in our analyses, highlighting the complexities of this pursuit and the multifaceted issues that can arise for families. We offer recommendations for research and practice aimed at expanding access to this much-needed—but often elusive—family support.

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“It’s So Tough!”: Barriers to Respite Care for Families of Children with Disabilities

More than one million children and youth with intellectual and developmental disabilities (IDD) live in communities throughout the United States (U.S. Department of Education, 2023). These young people can be a source of great joy, love, and flourishing within their families (Beighton & Willis, 2019). At the same time, the nature of their disabilities heightens their need for ongoing and intensive support. Indeed, the educational, behavioral, medical, and other multifaceted needs of children and youth with IDD can be quite complex.

Parents of children with IDD face distinct challenges (Hodapp et al., 2019). Although raising any child requires considerable time, energy, and resources, the additional support needs of young people with IDD can amplify these demands. For example, many children and youth require extensive or round-the-clock care that profoundly affects caregivers’ routines, sleep, employment, and relationships. Finding, fighting for, and accessing needed services or therapies can be time-consuming, expensive, and exhausting. Moreover, barriers of attitude and accessibility can limit whether and how these families participate in their communities. The collective impact of these myriad challenges can contribute to heightened stress, fatigue, loneliness, depression, and health problems (Enea & Rusu, 2020; Masefield et al., 2020; Miodrag & Hodapp, 2010).

Respite services represent a unique and powerful source of support for these families. Respite care is a short-term break designed to provide temporary relief to family caregivers (Kirk & Summers, 2020). Such services vary widely in length, timing, location, and cost, as well as whether such care is provided informally (e.g., friends, family, faith communities) or professionally (e.g., agencies, organizations, health care providers). Regardless of its source, the impact of respite care on parents and other family members can be profound. Studies examining the benefits of respite care for parents point to the provision of rest, reduced stress, improved mental health, strengthened marriages, reduced isolation, and opportunities to attend to other needs (see reviews by Robertson et al., 2011; Strunk, 2010; Whitmore, 2016). Access to periodic respite care can govern whether the daily challenges of parenting a child with disabilities lead to crisis (McCubbin & Patterson, 1983). Moreover, the holistic effects on the entire family—including children with disabilities and their siblings—are promising (Otsuki et al., 2020). Unsurprisingly, families hold great hopes for access to this critical form of care (Lanchak et al., 2024; Murphy et al., 2022).

Unfortunately, respite care remains an unmet need for most families (Ferragamo et al., 2022; Murphy et al., 2022). A growing number of international studies have explored factors that can hinder the receipt of respite care, including in Australia (Welsh et al., 2014), Belgium (Dubois et al., 2023), Canada (Doig et al., 2009), and Ireland (Caples & Sweeney, 2011). Prominent barriers included the paucity of providers, the length of waitlists, the financial costs, and the quality of services. In the United States, two studies have addressed salient barriers. Whitmore and Snethen (2018) interviewed 22 parents of children with special healthcare needs who raised concerns about the costs, fit, and quality of respite care. In their analyses of the 2005/2006 and 2009/2010 National Survey of Children with Special Health Care Needs, Graaf and colleagues (2022) reported the most common barriers focused on service availability, transportation, cost, awareness, and service times. Additional research is needed to capture a more recent and comprehensive portrait of prevailing roadblocks to respite care services.

The purpose of this study was to examine the barriers that keep families of children with IDD from accessing respite care. We sought to map the range of issues that can arise as parents pursue these much-needed services. Using in-depth interviews, we were also interested in capturing the weight and impact of these barriers for families.

Method

Participants

Thirty-one parents of children and youth with intellectual and developmental disabilities participate in this study. To be included, they must have been parents or primary caregivers to a person with disabilities who was receiving overnight respite care through a multi-state respite provider. Our sample included 20 mothers and 11 fathers representing 26 different families. In terms of marital status, 74% were currently married, 13% were divorced or separated, 10% were single, and 3% were widowed. In terms of age, 36% were in their 40s, 45% were in their 50s, 16% were in their 60s or above, and 3% did not report their age. Racial/ethnic diversity was 77% White, 10% Asian, 7% Black or African American, 7% Hispanic/Latino, 3% American Indian or Alaska Native, and 3% did not report (multiple options could be selected). Most had a college degree, including 3% with an associate's degree, 29% with a bachelor's degree, 42% with a master's degree, and 10% with a doctoral degree. Likewise, most parents were employed either full-time (65%) or part-time (10%). Their number of children averaged 2.6 (range, 1-7). When asked how well their respite needs were being met, 7% said *not at all*, 33% said *barely met*, 40% said *adequately met*, 20% said *pretty well taken care of*, and none said *perfectly met*. They resided in multiple states and described their communities as rural (3%), urban (45%), and suburban (52%).

These parents had a total of 27 children with IDD who ranged in age from ten to 23 years (*M* = 14.3 years); 52% were female and 48% were male. Table 1 displays information about their disabilities, reported challenging behavior, primary communication modes, and mobility modes. When asked about the level of support their child required, none said *no support* or *a little support*, 34% said *some support*, 56% said *a lot of support*, and 10% said *total support*. Many used an alternative means of communication (e.g., pictures, communication devices, gestures).

Recruitment

Participants were purposely selected from among more than 200 respondents involved in a larger survey study of all parents whose children were being served through an established respite provider. Although the organization provided respite in six locations across five states, the majority of families they served resided in a large metropolitan area. We used purposive sampling to invite a subset of participants for interviews based on their survey responses, striving to obtain a diverse sample with regard to gender, race/ethnicity, marital status, household size, and community type. We were also interested in hearing from some couples within the sample. We identified 50 parents to potentially invite, but ended recruitment as we experienced saturation (i.e., new barriers were rarely emerging) and our sample was representative of families utilizing [organization masked for review] services. We followed procedures approved by our institutional review board (IRB).

Interview Procedures

We held 28 interviews over 1.5 months, which included speaking with three couples together and two separately. All of the interviews took place through a video conferencing platform (i.e., Zoom), except for three that were held over the phone. The interviews averaged 43 min (range, 19-67 min) and were audio recorded. Three team members conducted the interviews, one interviewer per parent. All team members had disability experience; one was the parent of a child with disabilities. Each received training on the interview protocol and procedures.

We developed a semi-structured interview protocol (available by request from the first author) based on prior research (Murphy et al., 2022; Strunk, 2010; Whitemore, 2016) and aligned with our goal of eliciting a comprehensive list of barriers to respite. Each interview began with introductions, a reminder of the study’s purpose, and a review of consent information. We asked a series of questions addressing five primary areas: (a) reasons for pursuing respite, (b) availability of respite, (c) impact of respite, (d) other needs, and (e) recommendations for supporting families' respite needs. For the present article, the most relevant interview protocol questions were: *How hard or easy has it been for your family to find respite when you need it? Describe some of the barriers to accessing respite care.* However, discussion of barriers naturally occurred throughout the interviews as well. 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]?) to encourage clarification and elaboration. Each interviewer took notes and completed a post-interview reflection document.

Data Analysis

We began by ensuring all audio recordings were professionally transcribed, checked for accuracy, and carefully de-identified. We adopted a team-based approach to coding that involved five people: two graduate students studying special education or school psychology and three faculty members with expertise in the field of disability. Throughout the coding process, we strived to temper our own views and foreground the voices of families. Each member of our team has pursued careers focused on helping children with disabilities and their families to thrive in all areas of their lives. We are firmly committed to ensuring families can access the services and support needed to flourish in all areas of their lives. In our work, we hear often about the barriers families encounter in their pursuit of needed services and hoped this study would help pinpoint areas of particular struggle related to respite.

We used thematic analysis to address our research questions. Our practical goal was to compile a comprehensive listing of barriers that might hinder access to respite care, while also identifying those categories of barriers that garnered the most emphasis. Data analysis occurred in multiple stages. First, team members independently read 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 an initial list of barriers, developed tentative definitions, 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. We applied codes from the initial framework or generated new ones 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 update the coding framework into categories and subcategories based on key similarities. After discussing our coding 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 to organize our codes and summarize 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. First, we adopted recruitment strategies and inclusion criteria to ensure each participant had firsthand experiences related to the pursuit and use of respite care. Second, we kept a detailed audit trail of our procedures. Third, we used a collaborative approach to coding that combined investigator triangulation and consensus building as a check on individual biases we may have brought to this work.

Findings

Parents identified 15 salient barriers to accessing respite care for their family (see Table 2). In the following sections, we discuss the nature and impact of each barrier. The race or ethnicity (A: Asian, AA: African American, AI: American Indian/Alaskan Native, H: Hispanic, W: White) and marital status (M: Married, S: Single, D: Divorced, W: Widowed) of parents are indicated in parentheses. All parent and child names are pseudonyms.

Trust

Trust influenced the decision of 12 parents to pursue or use respite. Their limited confidence in the capacity of others to adequately care for the child was often framed broadly. As Nicole (AA, S) shared, “I trust no one. I’ve trusted no one for many years.” Frederick (AI, M) echoed this concern of many parents stating, “It’s difficult for us to trust.” Tammy (W, M) articulated this same reluctance when asked about barriers, “I can’t trust just turning him over to somebody I don’t know. So, that’s what my initial thought was.”

Some parents referenced their child’s limited communication abilities as amplifying the importance of cultivating deep trust. Kathryn (W, M), whose daughter has complex communication needs, remarked, “We’ve been extremely careful about who we’ve allowed to take care of her. Because we don’t want anything bad to happen to her. And we don’t know if she can tell us if something bad happens to her.” This uneasiness was affirmed by two other mothers. Leslie (W, D) shared, “It’s so tough! It’s a hard thing to trust somebody to take care of your kid, especially a nonverbal child. You don’t really know what’s happening.” Likewise, Emily (A, W) voiced her fear of what might happen to her son in her absence: “That’s scary with a kid that can’t express like: ‘This person hurt me’ or ‘This happened.’ They can’t say any of that.”

Past incidents provided context for some parents’ constrained trust of respite providers, including haunting previous experiences and prior medical traumas. Frederick (AI, M) shared how his family “had some pretty terrible experiences” that made it “really hard for us—for me—to trust.” Likewise, Andrew (W, M), a pediatrician, recalled a medical emergency from years earlier when his now 17-year-old daughter was an infant that still fueled his hesitation to trust her care to anyone else. “There [has been] a huge mental barrier to being comfortable leaving her with someone else. We’d ask all the questions—like CPR and all that stuff—all the basic things, I guess. But we were very nervous too!”

Parent Hesitancy

Nine parents expressed apprehensions about enrolling their children in respite care programs. Concerns about their child’s safety and/or a program’s credibility shaped their decisions. This fear sometimes stemmed from past experiences of neglect or abuse in other contexts. Verónica (H, M) described how fear “lives in the back of my mind. I’m also paranoid because I’m like, ‘Okay, I don’t know enough about this program.’” Even when they knew their program was reputable, worry still lingered for some parents. Other parents were concerned about whether staff had the competence to care for their child safely. As David (W, M) explained, releasing his son to anyone was “a little bit of a scary proposition.” Shelley (AA, D) was quite candid about why she hesitated to access respite from just anyone, “There’s no way anyone can take care of my child the way I can.”

Parent’s Perception of Child’s Needs

Sixteen parents held views about their child that impacted their pursuit of respite. More specifically, perception of their child’s behavior was a primary reason for not considering respite care. Rhonda (W, M) shared about her initial reluctance, “I was apprehensive at first because I didn’t think that he would behave well and that he would miss us. Yeah, I was just concerned about sending him away from home.” Erika (W, M) described feeling similarly, “I mean, it wasn’t like I couldn’t leave Lacey with somebody else. But it’s just that she was so difficult at that time. She would still elope, she would run off, and if we just tried to go to the park or something, she would run away.” Amy (H, D) shared that she considered respite earlier in her child’s life. But when her daughter’s significant behavioral challenges emerged, “We thought that there’s just no way.”

Other parents, like Jackie (W, M), wondered whether their children were really ready to participate in respite. She explained, “Early on in the process, I was like, well, I’m not really sure if he’s ready to do an overnight camp just yet.” Leslie (W, D) went even further in questioning whether her daughter would be okay in the care of anyone else: “I would never send my baby anywhere. Nobody else could ever take care of her. Are you aware she’s non-verbal? Who would ever be able to take care of her? No way. No way!” Knowing their particular needs and circumstances, many parents were unsure whether their children would do well unless strong support was available. Emily (A, M) was convinced it takes a “special person to care for somebody with special needs.” Likewise, Crystal (W, M) expounded, “Your children are different. They have more complexities. And you have to have somebody that really wants to do it. Finding those people is not easy.”

Lack of Family Support

Four parents recognized they had few family members to turn to for informal respite care. For example, Leslie (W, D), a single mother whose teenage daughter has extensive support needs, said, “I don’t have any family in the area. I don’t have any family even externally that I can lean on. It is just me.” After her divorce, Leslie’s circle of extended family support narrowed dramatically. Gregory (W, M), the father of four children, found that his respite options diminished when his mother-in-law died. Now, he said, he and his wife “don’t have much support really.” Even when relatives were available, some parents felt care would not be possible because they “don’t understand what [my child] needs” (Verónica, H, M).

Reluctance to Seek Help

Four parents expressed some reservations about seeking respite from family, friends, or formal programs. In some cases, they worried about imposing on or inconveniencing others. For example, Yuuko (A, W) explained how she has a “self-imposed limit” on what she asks of her mother because she “[does not] want to burden her too much.” For other parents, this reluctance emerged from a sense of guilt that they might be taking limited opportunities from others whose needs are greater. Diana (W, M) wondered aloud, “Were we taking this away from someone else who was more deserving or needed it more?” Verónica (H, M) felt similarly when first reading about local respite offerings, “I never signed her up. I always thought respite care was for kids that were very high needs or severely disabled or needed constant care…I shouldn’t be asking for anything because of [my daughter’s needs]…I felt guilty.”

Lack of Availability

Six parents described the absence or paucity of respite offerings in their local area. Paula (W, S) said it simply, “There just are not enough!” Similarly, Tammy (W, M) noted, “There just aren’t very many programs.” Even well-informed families struggled to locate opportunities. Brittany (W, M), an experienced special education teacher, illustrated this challenge, “I’m good at knowing what resources there are and how to help access them to help my children…Even with that advantage, I’m just telling you, there’s not a lot [of respite] out there.” Likewise, well-resourced families also found few options. Gina shared, “We’re lucky we have a nanny, but that’s during the days to get her from point A to point B. I don’t feel like that’s as much respite. It's like I'm working while we have a nanny.”

Lack of Awareness

Eleven parents described how hard it is to find respite offerings that are offered in their area. Speaking about an overnight respite program she regularly accesses, Nicole (A, S) explained, “Not everybody knows about the program…I tell everyone I meet with a disabled child. I do! Because these services are not known to everybody.” Frederick (AI, M) agreed, “They’re tough to connect with.” Andrew (W, M) suggested the challenge of awareness might go even deeper, “Most families don’t even know what the word respite means.” As a result, they may not know what to look for in their search for help. Respite care providers should “advertise more” and “[get] the word out more” so parents do not, as Veronica (H, M) put it, rely on finding these critical resources “by luck.”

Eligibility Criteria

Ten parents described how stringent program qualifications further constrained their respite options. Having a child who was too old or too young, who lacked the right diagnosis or medical documentation, or whose support needs were too high or low—kept them from accessing existing offerings. Age restrictions were regularly mentioned, particularly among parents of youth and young adults. Shelley (AA, D), the mother of two children, grieved “the lost weekend stays” when her disabled son “aged out” of existing respite programs after turning 23. Andrew (M, W) commented that “I’ve looked pretty deeply and there’s just not a lot out there.” Leslie (W, D) also emphasized the aging-out problem, “It would be absolutely awesome to have a place where [my adult daughter] could go and have similar social, fun, joyous experiences. And I get the break that I need. Man, do I need it! Really.” Other eligibility requirements also impacted options, including those related to disability and income. Felicia (W, M) shared, “There’s really not a lot of places that can care for Carson…because he just needs more supervision than their [staff-to-client] ratio probably allows.” Diana (W, M) added, “A lot [of programs] require a Medicaid waiver to pay for respite services, others require specific diagnoses and going to a doctor to get that diagnosis to qualify is another form of barrier.” Many parents were left wondering, “Where does [my child] fit in?” They wished someone could help them locate respite services for which they were eligible.

Waitlists

Eight parents cited long waits as a roadblock to accessing needed respite. Christopher (W, D), the single father of two children, described his experience as “sitting around for a few years and, when you finally get called, then it's 'Alright, get all this information in!'" This prolonged wait for an opening made it difficult for parents to manage their day-to-day responsibilities and plan for their child's future needs. Shelley (AA, D) observed how the need for timely respite is most pronounced among "the younger families who are really, really struggling to keep above water." Most of these parents also mentioned other barriers (e.g., eligibility requirements, complex processes, lack of awareness) that kept or delayed them from even getting on a waitlist. Frederick (AI, M) attributed the ubiquity of waitlists to the scarcity of respite options, noting, "There's not a lot of programs." The unpredictability of "never-ending waitlists" exacerbated stress levels and fatigue, keeping families from receiving restorative rest.

Complexity of the Process

Sixteen parents shared the complexities of applying for formal respite. The "long drawn-out [intake] process" and "giant piles of paperwork" required to access respite care were among the myriad hurdles they described. Yuuko (A, W), a single parent of three children, described it as "a lot of desk work—*many* hours over *many* days and weeks." The laborious process led some parents to forego enrollment altogether. Tammy (W, M), the mother of several children, offered context for this challenge, "I'm working *and* taking care of my other children. You just don't have the time and energy and the resources when you're dealing with all this other. And [yet] it's what you need the most." Comparably, Gina (W, M) said, "There's a lot of red tape. There's always a lot of forms with our kids." Melanie (W, M), whose daughter requires 24-hour care, conveyed how hard it was to apply for respite, "At the time, their website was such that you couldn't save [your application] and I couldn't find the key to save it. And so, I would spend an hour filling everything out and getting it all done and then it would all be lost. And I did it three times!" Brittany (W, M), the mother of three children, asserted, "If anybody was going to be deterred from doing [respite], the deterrent might be how involved the process to getting your child there is." Felicia (W, M) shared similar frustrations, saying, "It [takes] follow up for some places just to get back to me … some would just go to a voicemail, and I just don't know what happened."

Program Configurations

Twelve parents referenced the ways in which the timing, frequency, duration, or regularity of respite offerings could hinder some families from participating. In some cases, the timing of available respite was inconvenient or incompatible with a family's schedules or needs. Some parents felt they had to jump through hoops because respite was offered at times that just did not work well. Wearily, Nicole (AA, S) noted how "the timing is never good" for her. She was not alone. Yuuko (A, W) remarked how the scheduling of respite often discouraged her from participating. Instead, she said she relied on "some combination of my mom and the nanny" for respite care. The frequency and regularity with which respite was typically offered also felt insufficient in light of some family's pronounced needs. Leslie (W, D), whose daughter received respite a few times each year, longed for much more: "I really wanted it to be once a month. And I knew that wasn't going to be possible. There's just so many people who need it." Finally, some parents addressed how the duration of most respite impacted their involvement. For Gregory (W, M), the long drive "back and forth and back and forth" to the nearest respite location meant short experiences of just an hour or two were just not worth the effort.

Financial Barriers

Nearly half of parents identified finances as a barrier. The high costs associated with some respite programs presented a considerable challenge for many of these families. Kathryn (W, M) expressed her shock when researching summer program costs for her 17-year-old child, "This camp is $17,000! Who could pay that?" Other parents, like Verónica (H, M), gave up pursuing respite care due to financial constraints, "[It is] cost prohibitive. If I'm going to pay [by the] hour and I’m going to pay that much, I might as well keep her at home.” Searching for financial support was itself a challenge. Andrew (W, M) noted how “there’s no money for it. When are you going to find time to do paperwork to get on [financial] waitlists too?” A few parents referenced the impact of insurance coverage on respite access. Caps on the number of respite hours per year directly impacted those families. Amy (H, D), whose daughter has extensive support needs, explained, “They don’t understand a family like ours—where that weekend respite that’s now been taken away—how profoundly that affects us…Her respite hours from the state wouldn’t have covered 12 visits a year.” Finally, some parents felt they were at the mercy of how agencies allocate respite funding to families. Christopher (W, D) expressed the feeling of powerlessness and stressed bluntly, “It’s like you have a gun to your head.” Similarly, Nicole (AA, S) was frustrated by rules that led to her loss of funding, “I lost that 480 hours [of funding from waivers] because I didn’t receive my respite for nine months…that was a loss on my behalf.”

Program Quality

Eight parents described concerns regarding the standards of most available respite offerings. Some expressed their significant reservations about accessing formal respite programs without high confidence in their quality. Describing the meager respite opportunities in her community, Tammy (W, M) observed, “In general, there just are not enough and [they] could be improved upon. I will say—just not the highest quality, many of them.” For Kathryn (W, M), having *only* low-quality options was the same as having *no* options: “There are a lot of bad programs out there for kids with special needs that just aren't very structured. I'm not willing to put her in a bad program just so I can have free time. I’d rather have her with me if it’s not going to be a quality program.” Programs whose staff were insufficiently trained or experienced were simply not considered viable options for families. William (W, M), the father of two daughters with extensive support needs, emphasized this challenge:

> It's just the ability of having people that you trust and that have the level of training. And also the level of willingness to be able to come in and take on that level of responsibility for a long time to be able to do that. Again, I think there's a certain level of training that's necessary and a certain level of compassion that again, is not that easy to be able to come by.

Other parents described the persistent challenge of finding adequate in-home support for their child with disabilities. Nguyen (A, M), whose son has significant challenging behaviors and limited communication, illustrated this obstacle: "I try to hire sitter to watch him, but most sitters doesn't know what to do with him…So, I don't feel comfortable to leave my kid alone with the sitters." Amy (H, D) emphasized this as a widespread challenge:

> There's always, always barriers! I used to have a support group on Facebook of 2,000 moms who have a child with autism…And that was always a difficult situation in finding respite. Because you could hire somebody from care.com or put an ad somewhere, but the chances that they had experience with someone who had special needs was very low.

Getting There

Fourteen participants addressed the very real logistical challenges of actually getting their child to respite offerings, including the sheer distance, extended travel times, and work schedule constraints. Susan (W, M) likened their "hours of traveling" to respite programming to "spending our whole life in the car," which eventually led them to abandon this pursuit. For Shelley (AA, D), the time required to get her son to respite squeezed other activities out of her life. She explained, "I make it a priority to get him to his programs, but I don't do anything else outside of that because of the distance." Even if the distance was not substantial, traffic patterns sometimes made the travel time untenable. Speaking of one opportunity in a nearby town, Yuuko (A, W) clarified, "The distance would impact my decision of whether to do that [respite program] because during those hours in traffic from where I live to there. It would be significant." Gina (W, M) highlighted this challenge for weekend respite, "It's really hard on a Friday night to get people anywhere because traffic and everything is so bad. So, it takes several hours."

The time required to get their children to respite also impacted parents' ability to use the available time to relax. Emily (A, M) commented, "I guess that makes me not sign up for it, because I'm like, oh geez, that's a lot of back and forth and back and forth." Susan (W, M) explained how accessing overnight respite required a combined "four hours of traveling" on the day of drop-off and pick-up. "There was no respite involved. We had no relaxing. We barely could go out for supper before we have to go home, go to bed, because we have to get up early the next morning to go and pick him up and take him to school." Melanie (W, M) detailed her own calculations, "It is an hour and a half in traffic, it could be two hours each way…It does dent some of the respite."

Lack of Representation

One parent raised concerns about the degree to which respite programs were serving the diversity of families in her community. Nicole (AA, S) described respite access as profoundly unequal and "given to those that has privileges." She described the responses she received as she shared with others in her circles about the respite programs her son accessed: "I've heard people make the comment when I told them about [the program]: 'Oh, they don't allow our people.'" She felt strongly that respite programs should do more intentional outreach, "It shouldn't just be one basic large setting of certain families. It should be a diversity—all kinds: Indians, Chinese, Spanish, Black, Africans. Let everybody in because we all bleed the same!"

Discussion

The rest and renewal offered through respite can be a gift to families impacted by disability (Whitmore & Snethen, 2018). Indeed, every parent in our study spoke vividly about the importance and urgency of this very tangible form of care. For many families across the United States, however, access to this vital support remains rare or uneven (Graaf et al., 2022;

Kirk & Summers, 2020). We examined the array of barriers parents have faced when pursuing formal and informal respite. Our findings offer several important insights into the continued complexities of accessing respite services for families of children with IDD.

First, parents described a constellation of challenges that converged to limit their access to much-needed respite care. Although other studies have highlighted a sampling of the barriers families face in this area (Welsh et al., 2014; Whitemore & Snethen, 2018), we were struck by the multifaceted nature of this challenge within our sample. Specifically, we identified 15 different barriers to accessing regular respite care for their children with IDD. Some of these challenges related to locating suitable respite options (e.g., limited availability or awareness of offerings, meeting stringent eligibility requirements, finding options that worked well for the family), while others emerged from the sheer complexities of accessing these options (e.g., navigating the application process, perception of child's needs, enduring long waitlists, addressing affordability). Concerns about the design and quality of program offerings were also prominent, which sometimes diminished parents' eagerness to pursue an available option. At the same time, parents were also candid about how their own apprehensions could impact their pursuit of respite (e.g., limited trust in respite providers, reservations about asking others for help). Considered together, this collection of barriers suggests that accessing respite continues to be a complicated endeavor for many families of children and youth with IDD.

Second, the challenges families experienced were quite pronounced—both in terms of the number of different obstacles they encountered and the intractability of each barrier. Many of the stories parents shared illustrated the discouragement and exasperation they felt at the very point when their family most needed support. Moreover, the confluence of multiple barriers throughout the process of pursuing respite left many families feeling utterly overwhelmed or deeply frustrated. Of course, challenges in this area are not new for parents of children with IDD

(Abelson, 1999; Knoll & Bedford, 1989). Indeed, our findings join a chorus of studies that emphasize just how difficult it can be for families to access this form of care (Murphy et al., 2022; Strunk, 2010). At the same time, they illustrate the pressing need to substantially improve the accessibility and quality of respite care across the country. Despite longstanding calls to expand access to respite services over several decades (Kirk & Summers, 2020; Upshur, 1983), the pursuit of such care remains especially difficult for families.

Third, the barriers raised by parents were sometimes interconnected. For example, more than a third of parents shared how hard it was for them to trust others to take care of their children with disabilities. Other parents expressed a degree of fear about what might happen to their child in their absence. In both cases, limited confidence in the quality of respite programming often contributed to or exacerbated their concerns. Assuring parents that staff are well-equipped to meet their child's needs may be essential to addressing the reluctance of some families. Likewise, the complexity of the application processes may contribute to the reluctance of parents to seek out help and the scarcity of options impacts the length of waitlists. Coordinated efforts within and between service agencies and in collaboration with families will likely be needed to address this web of interrelated barriers.

Fourth, parents may be contending with an array of additional challenges alongside their pursuit of respite. For example, locating and accessing needed educational, medical, therapeutic, and recreational services can be especially arduous for parents of children with IDD (Gilson et al., 2017; Resch et al., 2010). Indeed, Lanchak and colleagues (2024) discovered that three quarters of parents found it somewhat or very hard to find the information or the help they needed to support their children with disabilities. As a result, some parents may struggle to navigate all of these needs at one time and would benefit from support and guidance.

Limitations and Future Research

Several limitations suggest areas for future research. First, nearly all of our participants resided in suburban or urban communities. Barriers to respite services may look different in rural communities in which there are fewer formal providers and distinct transportation considerations. Future studies should focus on the experiences of families living in smaller communities or more remote regions of their state. Second, most of our sample was married and the majority had a college degree. The experiences of single parents and those who have less formal education may differ in important ways. Additional research is needed to explore the barriers these families face. Relatedly, understanding more about potential culturally relevant barriers some families may face in pursuing, securing, and feeling comfortable using respite services is worthy of additional attention. Third, we asked parents to reflect back on their earlier experiences pursuing respite care. Indeed, all of our participants were ultimately successful in accessing overnight respite. However, this retrospective approach may have meant some parents forgot key details of their prior pursuits. Future studies should adopt a longitudinal approach in which parents are followed along as they seek out respite. Fourth, our exploration of barriers to respite focused only on the insights of parents. Respite providers could also speak to the barriers they encounter in designing and delivering respite, including difficulties navigating regulations, expanding offerings, reaching diverse families, ensuring affordability, building trust, and more. Future studies should incorporate the perspectives of others involved in the design and delivery of respite care.

Implications for Practice

Accessing respite services is an enduring challenge for many families of children with IDD. We offer several recommendations for expanding access to this vital source of care. First, the availability and accessibility of local respite options should be increased substantially. States should allocate more funding to support the growth of new and existing programs (Ferragamo et al., 2022). Likewise, faith communities and other community organizations can also play a role in offering short-term respite offerings (Carter et al., 2016) and raising awareness about the importance of this care. Second, many of the barriers parents identified were not attributed to a particular provider, but instead reflected community-wide issues. The paucity of suitable options should be addressed by convening community members for community-level reflection on barriers and possibilities (Bumble & Carter, 2021). No single program can address every need, highlighting the importance of collective efforts to expand opportunities and individual, flexible programs that allow for specific needs of different populations at the local level.

Third, respite providers should invite feedback from parents on their experiences locating, applying for, and participating in their services. Such insights could help providers identify roadblocks and pain points for families pursuing respite. Opening these lines of communication and implementing training programs for providers to address these challenges could also provide a pathway for building trust and addressing parents' concerns about the quality of available services. Fourth, parents emphasized how difficult it was to find and locate suitable respite providers in their community. The task of researching options and navigating the application process felt overwhelming amidst the other demands of family life and never-ending care for their child. Designating someone as a resource navigator could help more families locate and apply for respite services.

Regular rhythms of respite can be transformative for families of children with IDD. Unfortunately, accessing this impactful form of care can be both daunting and discouraging. Continued efforts are needed to address the constellation of barriers evident in the stories of parents participating in this study. We encourage future research, community-wide reflection, and targeted strategies and partnerships aimed at increasing the availability of local respite options for families.

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Table 1

Demographics of Children with Disabilities

Variable	*n*	%
Disability categoriesi[a]		
ADHD/ADD	8	29.6
Autism/autism spectrum disorder	13	48.1
Developmental delay	16	59.2
Intellectual disability	23	85.2
Learning disability	6	22.2
Medical or genetic diagnosis	13	48.1
Mental health condition or emotional/behavioral disorder	1	3.7
Physical disability	4	14.8
Speech language impairment or communication disorder	16	59.2
Visual impairment or blindness	3	11.1
Other	4	14.8
Frequency of reported challenging behavior		
Never	9	33.3
Yearly	6	22.2
Monthly	2	7.4
Weekly	5	18.5
Daily	3	11.1
Multiple times daily	1	3.7
Preferred not to answer	1	3.7

Primary method of communication		
Talking	19	70.4
Using pictures or communication device	3	11.1
Sign language	0	0
Gestures, facial expressions, sounds, or body movements	4	14.8
My child does not intentionally communicate with others	1	3.7
Primary method of movement		
Walks on their own	27	100
Walks only with someone's help	0	0
Uses crutches or a walker	0	0
Uses a wheelchair	0	0

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

Table 2

Parent-Identified Barriers to Accessing Respite Care

Barrier	**Definition**
Trust	Parents have limited confidence in respite providers to care for their child.
Parent hesitancy	Parents are generally apprehensive or fearful about their child's involvement in a respite program.
Parent's perception of child's needs	Parents are unclear about whether their child's need can be supported within respite programs.
Lack of family support	Parents cannot turn to extended family for informal respite.
Reluctance to seek help	Parents have reservations about asking others for help in the area.
Lack of availability	Respite options do not exist in their community.
Lack of awareness	Parents are not aware of what respite options are available.
Eligibility criteria	Age, diagnosis, income, or other criteria that must be met to participate in a formal respite programs.
Waitlists	The time between applying for and receiving respite is too lengthy.
Complexity of the process	The process to learn about and sign up for respite is overwhelming.
Program configurations	The timing, frequency, duration, and regularity of respite offerings are a mismatch for families.
Financial barriers	The high costs and limited assistance make respite services cost

	prohibitive.
Program quality	The implementation, staff, or other resources of the program are considered to be inadequate or insufficient for a child.
Getting there	The distance to the program or availability of transportation is prohibitive for a family.
Lack of representation	People who use respite all share similar characteristics that make others feel like it is not for them.