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"What Services?": Stakeholders' Perceived Unmet Support Needs for Parents With Neurological Disorders

« Quels services? » : les besoins de soutien perçus comme non répondus pour les parents ayant une atteinte neurologique

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Key words: Parenting with disabilities; Neurological disorders; Child rearing; Rehabilitation; Qualitative research.

Mots clés : Parentalité avec une incapacité ; troubles neurologiques ; éducation des enfants ; réadaptation ; recherche qualitative.

Abstract

Background. Knowledge about the needs of parents with neurological disorders who take care of young children is limited. **Purpose.** The overall aim of this qualitative study was to explore the perceived unmet parent needs, current supports, and potential solutions to optimize supports of parents with neurological disorders in early childhood in a Canadian setting. **Method.** Focus groups and individual interviews with parents ($n = 8$), spouses ($n = 5$), rehabilitation clinicians ($n = 8$), community partners ($n = 7$), and researchers ($n = 7$) were conducted with a total of 35 participants recruited using convenience sampling. Inductive iterative thematic analysis was performed. **Findings.** The participants identified the need for society to officially recognize parenting with disabilities, adjust public policies, increase the scope of public programs, consider child development and family well-being, and have barrier-free communities. **Conclusion.** Providing customized solutions that will adequately fill perceived service gaps is of utmost importance to address these families' needs.

Résumé

Description. Les connaissances sur les besoins des parents ayant une atteinte neurologique et s'occupant de jeunes enfants sont limitées. **But.** L'objectif global de cette étude qualitative était d'explorer les besoins des parents perçus comme non répondus, les soutiens actuels et les solutions potentielles pour optimiser les soutiens pour les parents ayant une atteinte neurologique et de jeunes enfants dans un contexte canadien. **Méthodologie.** Des groupes de discussion et des entrevues individuelles avec des parents ($n = 8$), des conjoints ($n = 5$), des cliniciens en réadaptation ($n = 8$), des partenaires communautaires ($n = 7$) et des chercheurs ($n = 7$) ont été menés auprès d'un total de 35 participants recrutés au moyen d'un échantillonnage de convenance. Une analyse thématique itérative inductive a été réalisée. **Résultats.** Les participants ont identifié la nécessité pour la société de reconnaître officiellement l'expérience de la parentalité des personnes ayant des incapacités, d'adapter les politiques publiques, d'accroître la portée des programmes publics, de prendre en compte le développement de l'enfant et le bien-être de la famille et d'avoir des communautés exemptes d'obstacles. **Conclusion.** Pour répondre aux besoins de ces familles, il est essentiel d'apporter des solutions personnalisées qui combleront de manière adéquate les lacunes perçues dans les services.

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Introduction

Parenting is a complex instrumental activity of daily living (American Occupational Therapy Association, 2020) associated with an important life transition (Slootjes et al., 2016). Although pan-Canadian parent statistics are lacking, one recent provincial study found that women with neurological disorders (e.g., cerebral palsy, stroke) represent the second largest reproductive-aged subgroup (Tarasoff et al., 2020). However, women with disabilities remain largely unacknowledged, and their parenting rights may be compromised, even in Canada (Gibson & Mykitiuk, 2012). Parents with neurological disorders may have heterogeneous needs throughout pregnancy, childbirth, and childrearing, amplified by variable disease onsets, progression, symptoms, access to care plans, accessibility needs, and support availability (Barghouthi et al., 2020; Handberg et al., 2020; Pituch et al., 2020).

Though parenting is intrinsically demanding during early childhood, it is more challenging for parents with neurological disorders who are not receiving adequate support (Harris Walker et al., 2021; Morriss et al., 2013). However, unlike work-related, mobility, or self-care needs, interventions specific to parenting are lacking in occupational therapy (Edwards et al., 2014; Harris Walker et al., 2021). Though occupational therapists are skilled to facilitate perinatal occupational performance (Slootjes et al., 2016), clinical services gaps have been reported by both parents with physical disabilities (Powell et al., 2019) and occupational therapists themselves (Lampe et al., 2019). For this trend to be drastically changed, not only would it be important to document the perspective of parents and spouses on their unmet needs, but also the perspectives of key stakeholders knowledgeable of their needs and of potential support solutions that can be imagined within rehabilitation and community services.

Considering the support gaps for disabled parents worldwide, we chose to examine support needs within the context of a province in Canada where in 2009 the provincial government adopted a policy specifically aimed at increasing the social participation of people with a disability. This policy called for "innovations" (p. 32, OPHQ, 2009) to support parents with disabilities and meet childcare needs. Within this same province exists, to our knowledge, the one disabled parenting rehabilitation service in Canada, namely, the *Parents Plus Clinic*. Here, parents with neurological disorders caring for children under the age of 2 are eligible to receive public community occupational therapy services (CIUSSS CSMTL, 2022). Until now, more than 1,100 parents have accessed funded adaptive parenting equipment (Clinique Parents Plus & CIUSSS CSMTL, 2019) and other interventions (e.g., practicing baby routines, teaching safe use of equipment, using adapted parent techniques). Additionally, some not-for-profit community organizations in the province have recently committed to supporting parents with disabilities by creating tailored resources such as a position for a collective disability rights advocacy agent (Ex aequo, 2018) and an information guide specifically developed for parents with disabilities (AQPPT, 2021). Likewise, with accessing up-to-date information often being reported as a barrier in the parenting literature (Guerin et al., 2017), researchers in the field may offer added insights on existing support gaps and evidence-based forms of supports.

As most multi-participant studies to date have been limited to mothers with a disability (Payne et al., 2014; Prilleltensky, 2003), approaching the topic from a multi-stakeholder perspective, including occupational therapists, may offer a heightened understanding (Ivanoff & Hultberg, 2006) of the unmet support needs of parents with neurological disorders. Hence, the overall aim of this qualitative study was to explore parenting with neurological disorders in early childhood in a Canadian context. More specifically, the threefold objectives of this study were to explore from a multi-stakeholder perspective: (1) the perceived preschool 0–5-year-old parenting needs of parents with neurological disorders, (2) the existing supports available in relation with perceived needs, and (3) the potential solutions to optimize parenting supports.

Methods

A constructivist qualitative exploratory design (Guba & Lincoln, 1998; Stebbins, 2001) using focus groups (Desrosiers et al., 2020) and individual semi-structured interviews (Whiting, 2008) was conducted, embedded within an integrated knowledge translation approach with key stakeholders (Andrews et al., 2015). The use of two complementary data collection methods (Lambert & Loiselle, 2008) is particularly valuable when searching for an in-depth and collective understanding on a given topic (Ivanoff & Hultberg, 2006). Ethics approval was obtained from the first-author's research centre's research ethics board along with each participant's written informed consent. Clinicians' salaries were paid through research centre funds and received a complimentary lunch. All other participants received a monetary compensation (CAD$50) for the time invested in this study. To report our research, the COnsolidated criteria for REporting Qualitative research (COREQ) checklist was used (Tong et al., 2007).

Recruitment Process

Five participant groups with lived, clinical, or research experience of parenting with neurological disorders were recruited using convenience sampling (Patton, 2015): (1) parents with permanent neurological disorders, (2) significant others of parents with neurological disorders, (3) physical rehabilitation clinicians working in non-acute care settings, (4) community partners from not-for-profit organizations offering services to parents with disabilities, and (5) researchers. The target population was recruited by sending invitations to key clinical, community, and research organizations using mailing lists and publicly available data, word-of-mouth, and shareable social media postings. For representation purposes, critical case and typical case sampling strategies (Patton, 2015) were also used to recruit parents from the aforementioned disabled parenting clinic's mailing list. Participants were eligible to participate if they spoke and understood English or French. Parents and significant others were eligible if they cared for children under 10 years old and were interested to share their current or retrospective preschool experience. Clinicians, community partners, and researchers were eligible if they assumed present or past work with this population (e.g., parent activities or key publications). Master's-level and early-stage PhD students were excluded from the researcher group.

Data Collection

To facilitate active participation, five stakeholder-specific focus groups were held. As recommended, focus group size was established between four and eight participants (Desrosiers et al., 2020). Prior to the focus groups, sample demographic information was collected using stakeholder-specific forms. Participants received a plain language one-pager about the study's context, without disclosing the interview questions. The interview guide was developed and tested by the research team that included representatives from nearly all stakeholder groups. Data collection took place between January 2020 and May 2021. Ninety-minute, audio-recorded focus groups were planned, both in-person ($n = 1$) and virtually ($n = 4$) using password-protected licensed Zoom® meetings. The use of online synchronous focus groups (Abrams & Gaiser, 2017) was selected as a COVID-19 health measure.

Focus groups were moderated by two female co-moderators (EP and MA), both experienced in qualitative research. Co-moderators were a PhD Rehabilitation sciences candidate and occupational therapist (EP) and a psychologist and mother with a neurological disorder (MA) with past rehabilitation experience with a 2-year-old. One or two note-taker(s) were present to conduct live summaries and gather participants' related feedback during focus groups (Falter et al., 2022). All study participants could provide follow-up information, and three participants requested to participate in an additional individual semi-structured interview. Additionally, interviews were suggested as an alternative measure for participants that could not attend the focus group ($n = 4$) due to limited availability. All individual interviews were conducted by one interviewer and scheduled between focus groups, informing triangulation considerations as the study progressed (Lambert & Loiselle, 2008). Recordings were transcribed professionally.

Data Analysis

Sample descriptive statistics were calculated. Qualitative data collection and analysis were done concurrently (Miles et al., 2020). Following verbatim transcription and data familiarization, an initial coding list was generated by three coders (EP, RBL, and TC). As data analysis progressed, significant quotes and short summaries of findings were added to refine the coding list and code definitions in Microsoft Word, guided by information power (Malterud et al., 2016). A three-step thematic analysis was conducted inductively (Miles et al., 2020): (1) *data condensation*, with three rounds of coding to group codes into larger categories; (2) *data display*, with iterative and organized linking of categories in relation to study objectives; and (3) *conclusion drawing and verification*, where final overarching themes were determined using a team consensus approach with attention to data triangulation across stakeholders. To support transparency, a random selection of one-third of the study material was independently coded by an external fourth member and revised by the first two authors. Finally, our cross-specialty research team's reflections (e.g., debriefing data collection meetings, virtual summaries of preliminary findings) and self-reflective tools (e.g., electronic logbook) enhanced the study's credibility and sincerity (Tracy, 2010).

Findings

A total of 35 participants were interviewed: eight parents, five spouses, eight clinicians, seven community partners, and seven researchers. Focus groups (range: 66–98 min) were on average twice as long as the interviews (range: 39–59 min). Most participants were female ($n = 31$), were French-speaking ($n = 26$), and had a university degree ($n = 28$). Besides two parent-spouse dyads interviewed separately, all participants were unrelated. Most parents and spouses had two children with the youngest being on average 2.36 years old (range: 0.67–7 years old) and nearly all ($n = 9$) reported having received adaptive parenting rehabilitation services from the *Parents Plus Clinic*. Parents had various primary diagnoses, with about one-third considered as neuromuscular and progressive. Clinicians, community partners, and researchers were similar in age (about 44 years old) yet differed in professional roles. Clinicians and researchers had various backgrounds, with occupational therapy being the most frequent ($n = 4$). We had no drop-off or no-show participants in our study. Additional participant demographics are presented in Table 1.

Five themes are described below. For each theme, select participant quotations reflective of the broad perspective of stakeholders are identified using participant numbers. A summary of findings is presented in Table 2.

Social Recognition and Public Awareness

First, participants shared a need for broader social recognition and public awareness of parenting with disabilities: "the first need […] which is fundamental and difficult to fill, is the need for recognition […]. Because it's true that parenting with a disability is still taboo, it's difficult to talk about" (Community partner 2). In that context, lack of awareness about parenting with disabilities could lead to notable consequences, as this participant further explained:

> The general public, front-line healthcare workers […] they know very little about [parenting with disabilities]. In fact, they do not know that people with disabilities can have children. So, they can dissuade couples, or interested people, because of their lack of knowledge. It's not on purpose.

Table 1
Participant Demographics (n = 35)

Characteristic	Parents	Spouses	Clinicians	Community partners	Researchers
Focus group participant	8*	4	8	7	4
Individual interview participant		1			3
Female (%)	6 (75.0%)	3 (60.0%)	8 (100.0%)	7 (100.0%)	7 (100.0%)
Age (years) mean ± SD	35.4 ± 6.4	36.0 ± 6.9	46.6 ± 7.5	41.6 ± 10.8	43.0 ± 8.8
Years of experience mean ± SD			19.1 ± 8.7	8.7 ± 8.1	
Highest education (%)	Doctorate (25.0%)	Bachelor's Degree (40.0%)	Bachelor's Degree (87.5%)	Bachelor's Degree (42.9%)	Doctorate (86.0%)
Range of professional roles or primary training (*n*)			Special educator (1), Social worker (1), Occupational therapist[a] (3), Physical therapist (1), Kinesiologist[a] (1), Psychologist (1)	Coordinator (3), Director (2), President (1), Psychosocial worker, and project leader (1)	Psychology (1), Occupational therapy (1), Public health (1), Social work (2), Women's studies (1), Epidemiology (1)
In couples (%)	8 (100.0%)	5 (100.0%)			
Number of children (mean range)	2.4 (1–8)	1.6 (1–2)			
Has child custody (%)	8 (100.0%)	5 (100.0%)			
Range of parent primary diagnosis (n)[b]	Stroke (suspected) (1), Cerebral palsy (2), Myotonic dystrophy (1), Charcot–Marie-tooth disease (1), Spinal muscular atrophy (1), Paraplegia w/concussion (1), Guillain–Barré syndrome (1)	Cerebral palsy (1), Guillain–Barré syndrome (1), Traumatic brain injury (2), Viral encephalitis (1)			
Disability onset before first or only child (%)[b]	6 (75.0%)	3 (60.0%)			
Range of parent mobility equipment (*n*)[b,c]	Manual wheelchair (4), Power wheelchair (4), Walker (1), Rollator (1), Cane (1), Crutches (1), Scooter (1), Electric handcycle (1)	Manual wheelchair (2), Walker (1), Crutches (1), Scooter (1)			

SD = standard deviation.
Note. *Three parents also wished to participate in individual interviews to provide follow-up information.
[a] Two clinicians also assumed clinical coordination responsibilities.
[b] Includes information disclosed by spouses regarding a parent with a neurological disorder.
[c] Some parents used more than one type of equipment.

The perceived need for improved knowledge was also highlighted for school and legal workers intervening with these families: "[professionals] definitely need greater awareness of the systemic biases [...] grotesquely discriminatory policies [...] like, you know, [child] custody being removed on the basis of [parental] disability" (Researcher 1).

Participants identified biases, stigma, and negative attitudes leading to unrealistic expectations toward parents.

Table 2

Summary of Perceived Unmet Needs, Existing Supports, and Potential Solutions Regarding Parenting With Neurological Disorders

Themes	Perceived unmet needs	Problems with existing supports available	Potential solutions to optimize parenting supports
Social recognition and public awareness	Awareness	Lack of social recognition about parenting with disabilities	Increase public awareness on disability and parenting
Supportive public programs and policies	Public programs and policies	Programs and policies minimally inclusive of the needs of parents with disabilities	Adjust existing programs to parents' needs in early, middle, and late childhood Recognize parenting with disabilities in public policies
	Finances	Inconsistent or lacking financial and subsidized supports	Implement an allocation and funding program for parents with disabilities
Publicly funded clinical programs	General and specialized care	Service discontinuity due to lack of knowledge of services, service gaps, delays, and geographical barriers Lack of specialized services for parents with disabilities	Provide a long-term continuum of care with individualized and coordinated clinical supports Encourage interdisciplinary collaboration during the preschool period, including remotely
	Clinical training	Experiences of stigma and ill-advised services from clinicians with lack of relevant knowledge	Provide formal training on parenting with disabilities using various educational strategies
	Information	Difficulty accessing information on parenting with disabilities Lack of perinatal support guidelines	Discuss the topic of parenting during rehabilitation with families Promote support networks, including peer support
	Human and physical assistance	Narrowness or disparity of available support Limited availability of adaptive parenting equipment during early parenting	Develop new parenting with disabilities services and resources Provide in-home parenting assistance Extend services to cover the 0–5-year-old period
Parenting supports aligned with child development and family well-being	Family-oriented approach	Lack of family supports lead to family life imbalance and negative experiences	Align child and parent supports Develop new services and resources congruent with families' needs
Barrier-free parenting in the community	Physical accessibility	Difficulty finding and accessing environments suitable for parents	Make services and resources physically accessible for parents
	Transportation	Issues with paratransit use	Adjust paratransit services to parents' needs

Others reported situations that became judicialized cases requiring costly, and at times ill-advised, legal help. Consequently, nearly all participants called for increased public awareness about persons and parents with disabilities:

> We need to normalize disability in society. We must talk about disability. We must show that people with disabilities are there, that they exist […] that they are evolving, talk about their sexuality, talk about the fact that they can be parents, that they can work, all that […]. I think that a program [for parents with disabilities] is necessary, but we must also question the way our society looks at disability (Community partner 2).

Talking about the possibility of parenting with disabilities and supports, supporting community partners, highlighting parents' "invisible" difficulties, and increasing common knowledge were the solutions suggested to increase public awareness. Research-wise, participatory action research with parents with disabilities and intersectoral initiatives outside the "disability world" (Researcher 5) were also suggested. Moreover, case-by-case accommodations facilitating parents' social participation were deemed a priority over one-size-fits-all approaches.

Supportive Public Programs and Policies

Second, the need for extended governmental support and public policies with a life course approach for parents with disabilities, namely, an approach that considers parents throughout their life role, was shared by many: "In the programs and services that the government develops, there is nothing specific to a parent with a disability. […] We don't think that children with disabilities, one day, they will become parents and they will need services" (Community partner 7). Even for existing policies, such as the *Equals in Every Respect* policy, one social worker noticed discrepancies for parents: "if we have a policy, it should be very clear, what people are entitled to. And 10 years later, it's [still] not clear" (Clinician 2). Indeed, participants reported numerous parent struggles with daycares, finances, and in-home supports, as for instance: "when you register for a [subsidized] priority daycare spot, if it's not accessible [and you refuse it], you go back […] to the bottom of the [waiting] list" (Community partner 7). Some parents reported being excluded from government support (e.g., social assistance) and dependent on their partner's income. One mother explained: "You know, my parents had a [disability] allocation for me until I turned 18, but (sarcastically), when you become an adult, you are no longer disabled" (Parent 6). Similarly, Spouse 5 highlighted that her family could not receive home support services because her husband's "difficulties were more cognitive" than physical and thus seemingly made them ineligible for support services. While some reported similar refusals, others reported having received some financial help (e.g., respite for caregivers, assistance with instrumental activities of daily living, childcare home adaptations).

Participants suggested solutions, including government funding and recognition for parents with disabilities. In examining all programs, Community partner 4 emphasized the need to ask "how [are parents with disabilities] going to be served? […] Project [parents'] need[s] and then adjust programs accordingly." Feeling left out, some parents even attempted, though unsuccessfully, to advocate with political representatives, enhancing the perceived notion that they had to "fight all the time" (Parent 6) and always "justify [their] needs" (Parent 4). Others suggested the need for specific policies that prioritize parents with disabilities:

> All [subsidized daycares should] have that in writing as a [top] priority. 'You are obliged to accommodate a parent who requires an accessible daycare' […] Normalize it for all. If they have it in their criteria, you know, it will be a bit of an obligation (Parent 3).

To cover assistance needs, some suggested the implementation of a financial aid program specifically for parents with a disability, including a dedicated "budget for specialized [parenting] equipment" (Clinician 4) and an allocation specific for them.

Publicly Funded Clinical Programs

Third, participants saw public programs as "essential" and even more so for parents with minimal support or financial resources. Clinical services were deemed necessary for in-home hands-on assistance and adaptive equipment to be offered by trained workers, across various healthcare settings, childcare activities, and environments. Accessing reliable information (about services and resources), having human, instrumental, physical and/or moral support, and learning how to safely participate in early childcare autonomously represented additional needs. One mother compared her needs to: "someone who has had an accident and is learning to do [everything] again, that's a little what we need, to learn to take on our full potential with a baby, and to adapt as we go" (Parent 3). The need for both general and specialized services was raised, namely, accessing services specifically dedicated to parents with disabilities and ensuring that general services are also adapted to their needs. The need for long-term and concerted services was also highlighted like this mother who shared: "*Parents Plus [Clinic]* offers [services] for up to two years, that's fantastic, but there are loopholes in there because after two years it's not true that we have no more needs, there are things that continue to be necessary" (Parent 4).

When reflecting on the clinical services they had received, some parents acknowledged that existing services were "fantastic," "really helpful," and "very responsive." For others, services were described as "difficult," "silo-ing," "confusing," "complicated," and even "dreadful" with challenges in finding, accessing, using, understanding, and/or coordinating services. Many participants like this father described the lack of specific services:

> I still have access to rehabilitation services […], but I mean, there's almost nothing geared towards parenting […] and having all the independence that I would like to have with the kids. So, yeah, I would say 'What services?' […] I want to completely assume my father role, I want to have my role, to be able to take part in childcare, [and] not just say, 'my spouse will take care of it' (Parent 8).

Amidst narrow eligibility criteria and regional service allocation differences, this father also reported that in-home assistance was made available for his self-care needs, but was difficult to obtain and maintain over time for his parenting responsibilities: "we continue to have difficulties, and we continue to have these needs, and it seems that […] we spend our lives […] waiting for someone, by some miracle, to decide [to help us]." Furthermore, some existing services (e.g., child welfare) were perceived as ill-equipped to support parents. Feeling ill-supported, participants reported either living, or anticipating, adverse outcomes regarding healthcare, family planning, maternity leave, respite, or return to work, thus potentially opening the way to child welfare involvement. Participants also voiced their concerns about service discontinuity, sometimes involving back-and-forth experiences and long delays, either in-between clinical settings or services, as shared by Parent 7: "Who am I going to turn to, which occupational therapist will follow me to give me a hand? Those are the questions we ask ourselves, because at one point we fall between the cracks."

Alternatively, parents receiving multiple different services were subject to a perceived lack of service coordination:

> Often times, moms are having to access multiple different types of services for themselves. [These service providers] don't necessarily speak to each other. So, they have their disability-related supports, they have their poverty-related support, maybe they also have their mental health-related supports. But they are sort of caught between this sort of web of services that doesn't necessarily work well together (Researcher 7).

Other participants pinpointed the lack of knowledge about existing services, such as Parent 1 who learned about the *Parents Plus Clinic* only 2 weeks prior to giving birth. Meanwhile, some parents were left to take it upon themselves to find solutions, by getting information from peers on social media or customizing their own childcare equipment. Service gaps for specific parent populations like parents with cognitive disabilities were issues of concern in addition to the overall lack of customized perinatal support guidelines. Some community partners and clinicians like this occupational therapist witnessed firsthand that parents were not always provided quality care:

> Even though I wanted to make them [hospital workers] aware [about my client's disability], I think that there was unfortunately a real form of prejudice, and on top of that, they were people in the rehabilitation field. I was really disappointed (Clinician 7).

To reverse this tendency, participants called for more government-funded services and resources for parents with disabilities in general, including specialized clinical and research-based parenting initiatives. The need for service continuity from pregnancy planning to long-term parenting was perceived as a priority by Researcher 2: "parenting is a role, and we're going to offer services and there's going to be a continuum [of care]. I mean, half of the problems that I've heard would kind of like be resolved." Increased frequency and duration of services (e.g., occupational therapy services, parent–child accompaniment for outings) for parents until the child is 5 years old or more was also extensively discussed, as shared by Parent 4: "there are going to be new needs, obviously, we know that [as I have] a progressive, degenerative disease. So, we must make it easier to access [services], we can't close the few doors that are already open." "To hopefully improve attitudes towards disability" (Researcher 7), other proposed solutions included training future and current service providers and governmental program administrators to expand current service offer and eligibility criteria to reflect families' evolving needs and hopefully provide more accessible care to parents and prospective parents with disabilities. In addition, collaborative interdisciplinary partnerships across programs and disciplines were encouraged across the preschool period to potentially limit the involvement of child welfare services. New resources (e.g., web-based parenting central) and models of care were also discussed (e.g., telehealth), such as providing specialized case workers who would advocate for parenting support services or clinical champions assisting less exposed providers to parents with disabilities. Finally, participants voiced the need that clinical networks supporting parents' long-term participation (e.g., cognitive-based interventions) be established.

Parenting Supports Aligned With Child Development and Family Well-Being

Fourth, a family-oriented approach was believed to be necessary on physical, cognitive, and psychological levels, as explained by Spouse 3: "There are many needs that are ultimately the needs of children." For example, the need for age-appropriate strategies was evident for one mother who hoped for guidance to deal with tantrums:

> He [son] runs, he doesn't listen to me, and he almost got hit [by a car] […] it's not because a child is two years old that everything is okay. […] you know, it's learning how to deal with it all (Parent 6).

Other parents wished that mobility aid provision be considered along with changing childcare requirements:

> I have a scooter, but it would be much more practical to have a power wheelchair, but I don't have the authorization [for that] now. I'm fighting to get a new wheelchair for outdoors, to be able to go to the daycare with my daughter (Parent 5).

Moreover, the need to support cognitive parenting skills (e.g., executive functioning), including for parents with cognitive impairments, was also identified by a few participants in considering how demanding childcare may be. Finally, the need for services oriented toward families' psychological and emotional support was also highlighted. Unfortunately, many participants shared their unsuccessful attempts at receiving such family supports. Researcher 7 summarized it this way: "people may experience multiple barriers to getting the support that they need," regardless of disability. This leads to mental health issues (e.g., exhaustion) or physical injury in some parents and partners. For some, the COVID-19 pandemic with the imposed full-time childcare at home, isolation measures, and added healthcare delays made it worse. Parent 5 stated that her "spouse is in charge of everything right now" and that "he does a lot, precisely because I am limited in the things I can do. […] So, it also complicates family life." On the other hand, some spouses admitted they "become worn out morally [and] mentally. So, if there is help at that level, for me, it would be essential because I see the caregiver as the pillar in this story" (Spouse 2). Spouse 5 recounted how ill-supported her family was when her partner sustained a traumatic brain injury during her second pregnancy:

> I imagine that if we had been offered services, including [for my spouse] with help for the children, and if I could have had psychological follow-up, I think that would have avoided a lot of pain and suffering in our home. I think we would have felt much more accompanied and supported in the ordeal we were going through. […] I think that they [services] were not adapted to my condition, they were not adapted to what I was going through, to my needs […] I looked for couple therapy, as well as help for the children, and [there was] nothing, nothing at all.

Similarly, Spouse 1 recounted the following lack of services for her children:

> When my husband was discharged from the hospital, I also asked for psychological help for my children, because my children had known a father who walks […] It's a lot of change and adaptation for them too. But because they are preschoolers, I was told that 'they were going to have very little memory as they got older of their dad walking'. But still. My daughter, you can tell that she was traumatized. [But] for preschool aged children, there's no help.

In considering the above, Researcher 1 suggested that solutions need to be put in place and integrated into a continuum of care: "ideally we could look at a child's developmental pathway, and then kind of a parenting pathway, and then align the supports to [both of] those needs." In parallel, parent workshops, parent and caregiver support groups, help lines, and community-based aid were suggested by participants as invaluable possibilities for “sharing resources and experiences” (Researcher 7) between peers.

Furthermore, given how demanding early childcare is, some participants suggested that subsidized respite be offered, in the form of nannying, drop-in daycares, or housework help.

Barrier-Free Parenting in the Community

Finally, participants expressed a strong need for more accessible indoor and outdoor environments: “I think that [accessibility] is a big gap in society. If he [spouse] wants to be able to take on his parenting role equally, he should have access to everything” (Spouse 1).

However, further barriers, like difficulty finding and accessing housing (family-size, adapted, and affordable rentals) and parenting services (e.g., daycares, breastfeeding clinics, parent groups, playgroups, children’s stores) due to physical inaccessibility (e.g., stairs, lack of wheelchair ramps), were extensively discussed, as exemplified by Community partner 4:

> All the shortcomings in terms of physical or architectural accessibility are present when you are a parent. […] To find a [subsidized daycare], now that’s a thing, we speak much about it with parents. When you add a ‘wheelchair accessible’ criterion, you better be patient, start your search when you’re 20 years old or like five years before your pregnancy to find one.

Similarly, participants identified many issues with transportation, including taxi (exempt by law from having car seats for children) and paratransit use. According to many participants, paratransit presented several issues with booking (i.e., in advance bookings, ill-informed clerks), feasibility (i.e., waiting periods, mandatory one-way trips, work-life balance scheduling issues), and physical challenges, all of which rendered it “unadapted for parents” (Clinician 4) and at-risk for children. Clinician 3 exemplified the issue at hand:

> The law requires that a child be seated in a car seat until nine years old. Parents with disabilities must provide the car seat, transport it, bring it to destination, and return it. They have a disability, they have a child, and they must transport, we don’t know how, a big heavy car seat in addition to the child. So, it’s [just] not possible.

Therefore, most parents were described as dependent on the support of accompanying persons to transport their children and access premises. Concurrently, missing accessibility-related information was seen as even more problematic amidst the existence of online daycare repositories.

Finally, a list of accessible daycares maintained up-to-date on government websites was suggested as an accessibility measure, possibly highlighting the lack thereof. To mitigate transportation issues and address family emergencies, car seat equipment and physical assistance could be provided by transporters, with the possibility of roundtrips (in and out of daycares) and last-minute bookings.

Discussion

To our knowledge, this is the first multi-stakeholder study on early parenting with neurological disorders shedding light on perceived parents’ needs, problems with existing supports, and potential solutions with a qualitative, rehabilitation, and community perspective. The following discussion is organized following our study’s three objectives.

Parents’ Needs

In recent years, there has been increased scientific interest in the needs of parents with physical disabilities in North American contexts, mostly regarding women seeking perinatal care (Mercerat & Saïas, 2021; Mitra et al., 2016). With cumulative data illustrating that people with disabilities have increased pregnancy rates (Brown et al., 2020) and experience documented high rates of poverty and unemployment (Morris et al., 2018), food and housing insecurity (Parish et al., 2009), abuse (Mitra et al., 2012), and single parenting (Camirand & Aubin, 2004), a reflection on potential parenting activity limitations is timely. Our study highlighted that parents with neurological disorders and their families have financial, housing, healthcare, childcare, accessibility, and social participation needs. With many interconnected needs left unaddressed by rehabilitation and community services, a shift from a personal care approach to a comprehensive family-centred care approach is warranted (Harris Walker et al., 2021; Powell et al., 2021). It also represents a valuable opportunity to invest wholeheartedly into parenting, an occupation long ago criticized as being neglected in occupational therapy (Llewellyn, 1994).

Services and Resources for Parents

The reproductive and parental rights of people with disabilities are included in the United Nations *Convention on the Rights of Persons with Disabilities*, which Canada ratified in 2010 (United Nations, 2006). However, despite Quebec and Canadian policies in place, our study findings question how parents’ rights are being addressed when multiple service gaps are identified (Gibson & Mykitiuk, 2012). Over the past 30 years, American parents’ rights have failed to be adequately protected, despite established civil rights laws (Long-Bellil et al., 2021; Powell et al., 2020). In our study, participants depicted striking differences between the support services provided to different families. Such discrepancies were perceived as being fueled by personal or family statuses, like the parents’ primary diagnosis (and resulting sequelae), civil status, family income, living location, mobility or equipment needs, children’s ages, and availability of informal support. Such concerns about eligibility barriers for mothers with disabilities (Gibson & Mykitiuk, 2012; Guerin et al., 2017), systemic and organizational gaps (Prilleltensky, 2003), and community accessibility (Kaiser et al., 2012) have also been raised by others.

Claims of parenting being inconsistently or inadequately addressed in rehabilitation (Edwards et al., 2014) are concerning, as they may trigger social and health inequalities and restrict parent and family participation. Unfortunately, few specific services for parents with disabilities exist (Morriss et al., 2013), and when services do exist, they tend to be known by a select few (Tarasoff, 2018), similar to the *Parents Plus Clinic* services mentioned in our study (CIUSSS CSMTL, 2022). In our study, one notable difference was that all parents with mobility needs received publicly funded babycare adaptive equipment recommended by trained occupational therapists, which is rarely the case worldwide (Harris Walker et al., 2021). However, as children grow older or as other mobility needs emerge, new pressing equipment needs may be left unanswered. When considering children's rapid changes in early development and possible parental neurological disorders-related functional declines, concrete actions should be taken in occupational therapy to prioritize the "doing" of parenting, by addressing parents' concerns, abilities, and contexts (Lim et al., 2022).

Solutions for Parents

Our participants suggested solutions that could mitigate adverse outcomes and have ripple effects on families' well-being, parents' empowerment and social participation, and child development. Although researching each potential solution's effect was outside the scope of this study, some of the proposed solutions, from disability-specific training for professionals (Guerin et al., 2017) to changes in policies (Gibson & Mykitiuk, 2012), have also been discussed elsewhere. For instance, to protect the rights of parents with disabilities, Albert et al. (2021) identified solutions for legislative advocacy in the United States. Challenging legislators' preconceptions through education and relationship-building with child welfare services (Albert et al., 2021) could be of interest in the present context. Advocacy, like many of our study participants did, is a potential solution (Mitra et al., 2016; Smeltzer et al., 2017), yet not always feasible for struggling parents. Adopting a life course approach (Long-Bellil et al., 2021; Tarasoff, 2017) that goes beyond babycare support services and prevents service discontinuity and family disruptions is another pathway to consider. This would require flexible, collaborative, and family-centred services that are inclusive of parenting (Handberg et al., 2020; Morriss et al., 2013). Intervention planning and home help provision (Guerin et al., 2017; Mercerat & Saïas, 2021) should also be further considered for parents in rehabilitation and others.

Limitations and Future Research

This study had limitations. Despite using a mix of sampling strategies, we recruited only a small sample of male participants. Most participants were highly educated, potentially not capturing the perceptions of participants with different socioeconomic and educational backgrounds. Though our data is not representative of all stakeholders and parent subgroups, it provides a worthy contribution to an under-researched topic. Furthermore, related parent-spouses ($n = 2$ couples) could have mutually influenced their perspectives, but this potential bias was minimized by the study's timeframe (focus groups set 2 months apart). Future studies should include more parents with different backgrounds to broaden our understanding, including single parents, parents involved in custody cases, and those who did not receive specialized parenting services. Although we encouraged multivocality (Tracy, 2010) by interviewing many participants, it would have been interesting to repeat some focus groups to gather cross-disability and cross-specialty perspectives in different settings. Finally, though focus groups and interviews generate different types of findings, such alternatives are often offered for pragmatic reasons (Lambert & Loiselle, 2008).

Conclusion

With increased pregnancy rates for populations with neurological disorders, it is important to attend to these families' needs by providing customized solutions that adequately fill perceived gaps in services. Our multi-stakeholder study highlighted that supporting parents with neurological disorders is an interdisciplinary endeavor with preventive and life course implications. Supporting these families has coinciding social, public policy, clinical, family, and community multi-level considerations.

Key Messages

- This is one of the first multi-stakeholder qualitative studies on early parenting with neurological disorders.
- Parents and their families report many needs left unaddressed by rehabilitation services during the preschool period. Participants identified lack of ongoing and consecutive care for parents, despite agreeing that they are entitled to some form of adaptive parenting services.
- Participants stressed the urgent need for new forms of community supports to meet families' needs and fill perceived gaps in services.

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