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Parent-to-parent support for childhood neurodisability: A qualitative analysis and proposed model of peer support and family resilience

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Abstract

Background: Qualitative studies have shown that peer support is of value to parents and other caregivers of children with neurodisability. However, this value likely cascades to other areas such as family well-being. There are various forms and functions of peer support, and how they operate is not well understood for this population. Models of family resilience theory can be helpful to situate the impact of parent-to-parent peer support processes within a family context to further explain how this type of assistance is beneficial. Our study aimed to describe the specific pathways by which peer support may contribute to resilience in families and how processes embedded in this type of support can enrich family resilience theory.

Methods: Using reflexive thematic analysis, we examined transcripts and notes from 19 interviews with parents of children with neurodisabilities regarding their involvement in a large ($n = 300$) and predominantly volunteer-based peer support network in western Canada. Using an inductive coding method, we identified patterns in the data. Following a process of reflection and discussion, we then used a deductive approach to situate themes within a family resilience theoretical framework.

Results: We identified three main themes from the data: Modifying belief systems through shared lived experience; navigating resources; and negotiating resources and engaging in social discourses. These themes confirm previous findings in the literature, and the subthemes demonstrate how they may contribute to broader family-level experiences beyond that of the parent.

Conclusion: We present a model for understanding how processes in peer support can be understood within a family resilience theoretical framework. We also propose that the reciprocity embedded within peer support builds upon previous concepts within family resilience theory. Future studies can use this theoretical framework to guide research questions to further explore the effects of peer support at the family and community levels.

KEYWORDS
caregivers, family, navigation, neurodisability, parenting, peer support, resilience

1 | INTRODUCTION

Parent-to-parent peer support is increasingly recognized as a tool for supporting families of children with neurodisabilities (Chakraborti et al., 2021; Shilling et al., 2013, 2015a, 2015b). Neurodisabilities are a group of long-term conditions related to impairment of the brain or neuromuscular system that create functional limitations (Morris et al., 2013). Persons with a neurodisability may have a diagnosis such as autism spectrum disorder, cerebral palsy, and Down syndrome or may have symptoms that do not fit into a specific or known diagnostic category. There are a number of studies that have identified possible pathways in which resilience can be understood in these families (Gunty, 2020; Leone et al., 2016). Others have previously demonstrated how family resilience frameworks are relevant to the qualitative experience of parents involved in peer support contexts (Dodds & Walch, 2022). Our present study represents a contribution to this literature insofar as we propose a theoretical model demonstrating how peer support and family resilience intersect. We developed this model through a qualitative analysis of interviews conducted with parents (or other caregivers in a parenting role) involved in a predominantly volunteer-based peer support network for families of persons with disabilities.

Several key, overlapping frameworks of family resilience theory may clarify how families thrive in the face of the adversity that is often associated with raising a child with a neurodisability. We will first briefly introduce relevant concepts within these family resilience theoretical frameworks and will later demonstrate in our results section how they apply to our population of interest, along with further elaboration in our discussion. First, Ungar's (2010) definition of family resilience suggests that for families to do well, they need to *navigate* adequately available resources (psychosocial and otherwise) and *negotiate* for them to be accessible in culturally meaningful ways. Second, the Double ABCX model of family adjustment and adaptation provides a succinct framework for organizing factors that affect family resilience, namely, the pile up of stressors experienced by the family, accessing internal and external resources, perception of balance of stressors and resources available to manage them, and the desirable outcome over time (i.e., how well the family adjusts and adapts to a family crisis) (McCubbin & Patterson, 1983). Third, Walsh's (2016) developmental systems framework identifies nine key processes of family resilience centred around family organizational processes, communication and problem-solving processes, and belief systems embedded within the family. Fourth, the functioning of one system can influence other embedded or connected systems, and this influence can cascade over time (Masten & Palmer, 2019). To this end, the act of parenting is a key mechanism through which parents, children, and their families navigate many of these dynamic resilience processes over the family lifecycle and across generations (Masten & Palmer, 2019). Parent-focused interventions may help facilitate family resilience through prevention of risk associated with parent well-being that may affect parental efficacy (e.g., treating parental depression); supporting to enhance parenting practices (e.g., parent training programs; housing and food security programs); improving systems that

Key Messages

- Parent-to-parent peer support for families of children with neurodisabilities operates through family resilience processes including modification of family belief systems and facilitating the navigation and negotiation of resources.
- The reciprocal and organic nature of peer relationships contributes to the maintenance of resilience processes within families as well as the peer support network in this study.
- Professionals should refer parents to peer support networks for opportunities to share and receive stories of lived experience, identify and access meaningful resources for the whole family, and to activate internal resources through reciprocal exchanges of knowledge and strength.

involve parents (e.g., family therapy); or through approaches that combine several of the above (Masten & Palmer, 2019). Based on these concepts and frameworks, we can situate the experience of parents of children with neurodisabilities within family resilience processes. However, the mechanisms by which peer support operates cannot be adequately described using any single one of the aforementioned concepts and frameworks. In the present study, we use qualitative data collected from interviews with parents to identify pathways by which parent-to-parent peer support can contribute to family resilience, borrowing from components of various family resilience theories. Additionally, we propose a model demonstrating the intersection of peer support and resilience processes.

2 | AIMS

The primary aim of the study was to better understand underlying processes embedded within interactions between peers offering, receiving, or coordinating support in the context of caring for a child with a neurodisability. Furthermore, we wanted to examine the quality of the relationships between parents involved and to explore how this knowledge about peer support processes inform or demonstrate an application of family resilience theory.

2.1 | Service context

The peer support network in this study is coordinated by a not-for-profit organization supporting families and persons with lived experience with disabilities in a western Canadian province. The network consists of over 300 peer support volunteers (referred to by the organization as 'resource parents'), paid regional network coordinators,

and other staff (FSI of BC, 2020). All volunteers and staff of the organization have lived experience caring for a person with a disability. A more in-depth description of the service context and type of support that is offered by the network is available elsewhere (McCrossin et al., 2022). While the organization's mission is to support anyone with any disability and their families, our dataset was limited to families of children with neurodisabilities.

3 | METHODS

3.1 | Recruitment and participants

Participants were recruited through convenience sampling. Our community partners in management roles at the not-for-profit organization identified and invited potential participants and obtained consent to share their contact information with the first author. The first author contacted 25 potential participants via email with an invitation to schedule an interview, details of the study, and an informed consent form. A total of 19 interviews were conducted between March 2020 and February 2022 with parents receiving support ($n = 4$), volunteer peer support parents ($n = 8$), and paid regional network coordinators or staff ($n = 7$). All participants were mothers with direct experience caring for children with neurodisabilities (see Table 1 for additional demographic data).

3.2 | Procedure

3.2.1 | Interview process

Three semistructured interview guides—one each for parents receiving support, parents providing peer support, and regional network coordinators—were developed in partnership with the research team and leadership representatives from the community organization. The questions were designed to elicit stakeholder experience of being part of a peer support network including benefits and challenges in their respective roles. All interviews were conducted by the first author over videoconferencing software and were audio recorded for transcription. The first author took extensive notes during and immediately following each interview. While most interviews generally lasted 1 h, some lasted longer and some were conducted over several sessions to adapt to the needs of participants and their families.

3.2.2 | Position of the interviewer

The first author was the sole interviewer and primary researcher involved in the coding and analysis of the data. He is also a social worker, couple and family therapist, and doctoral student whose research and clinical practice is heavily guided by family resilience theory.

TABLE 1 Parent and family demographic data

	Number of participants (N = 19)
Role of parent in the peer support network	
Parent receiving peer support	4
Regional network coordinator	7
Peer supporter (resource parent)	8
Age of parent	
30–39	1
40–49	10
50–59	5
60+	3
Age of person in care of parent	
School age (5–12)	5
Adolescence (13–17)	7
Young adult (18–30)	4
Adult (31–64)	3
Gross family income	
Less than $25 000	1
$25 000–$34 999	1
$35 000–$49 999	5
$50 000–$74 999	4
$75 000–$99 999	4
$100 000–$149 999	2
$150 000–$199 999	1
$200 000 or more	1
Identity as reported by parent	
Indigenous	4
Newcomer to Canada	1
English as a second language	2
Did not identify as belonging to any of the following groups: Indigenous, newcomer to Canada, English as a second language, or LGBTQ (lesbian, gay, bisexual, transgender, or queer)	12

3.2.3 | Data analysis

The design of the qualitative analysis of the interview transcripts evolved through an iterative process employing thematic analysis (Braun & Clarke, 2021). Following a reflexive thematic analytic process, "themes, developed from codes, are constructed at the intersection of the data, the researcher's subjectivity, theoretical and conceptual understanding, and training and experience."(Braun & Clarke, 2021, p. 18). A primary or single coder and analyst is a typical feature of this process that leverages rather than attempts to eliminate or control researcher subjectivity (Braun & Clarke, 2022). As such, the initial inductive coding process guided by family resilience theory was conducted by the first author with the reflective process

being enhanced through review of interview notes as well as discussion with the second author. All coding was done using Dedoose qualitative analysis software (Salmona et al., 2020). The coding was first conducted on an initial set of three interview transcripts to identify initial patterns in the data (McCrossin et al., 2022). The codes and themes were reviewed in discussion with the first and second author and then applied to the remainder of the dataset in a codebook style of analysis by the first author and a research assistant, primarily for pragmatic reasons (Braun & Clarke, 2021). Codes and themes were then revised by the first author through expanding and collapsing groups of excerpts during a phase of rereading the full set of interview transcripts and notes until the final themes were "internally coherent, consistent, and distinctive" (Braun & Clarke, 2006). All relevant extracts for each theme were collated. The most illustrative examples of each theme were incorporated into the results section below. The first author engaged in a final phase of deductive analysis whereby the latent meanings interpreted from the codes, themes, and interview notes were organized by concepts found in family resilience theory (Masten & Palmer, 2019; McCubbin & Patterson, 1983; Ungar, 2010; Walsh, 2016).

4 | RESULTS

Three themes were identified in this study that demonstrate family resilience processes. Each theme is described below along with subthemes and quotes from the interviews demonstrating how these themes were voiced by parents.

4.1 | Theme 1: Modifying belief systems

The first theme reveals qualities of peer relationships and how their shared lived experience is expressed through sharing and listening to one another's stories. As will be argued in the discussion section below, the application of lived experience facilitates modification of belief systems whereby parents develop new ways of thinking about their challenges, strengths, resources, and the future that lies ahead for their families.

4.2 | Subtheme: Lived experience is shared through reciprocal and organic relationships

Several participants noted that peer support is provided in a reciprocal manner that is distinctly different from the often-hierarchical relationships that exist between parents and professional care providers. For some, this reciprocity contributes to ease in requesting support, knowing that there will be an opportunity to give back. One parent noted that she preferred to seek the support of a peer from the network because she knows that they would be "willing to call in this favour" (Parent 4), whereas a neighbour, for example, may provide but not seek support from a family with a child with a neurodisability for

fear of overburdening them. This parent described the process of reciprocal support as empowering her to access the support she and her family needs. This process also supported the development of a family belief system around being active members of a community as opposed to being passive receivers of support.

Most participants mentioned a need for authentic connections. Many described their connections with peers as developing organically, or in cases where a formal connection was made through the network, the relationships tend to become less formal and more reciprocal in their nature. Several participants in the study reported "wearing different hats" as peers as well as health or social care professionals. One network coordinator explained that even for those with professional roles within or outside of the network, they always introduce themselves first as parents because, if taking a professional stance,

> It sounds like you're going to be told what to do. And we've got enough professionals that think they know what they're doing in our lives. (Network coordinator 7)

A parent receiving support explained that she was more at ease to share her authentic emotions with a peer as opposed to a professional.

> Well, I did breakdown in front of a few professionals, but I felt like my relationship had not benefited from it because it was more awkward ... a professional's like 'Oh, what do we do with this?' 'How do I solve this?' There's no solving it. (Parent 4)

She went on to explain that because peer supporters do not enter the relationship with an agenda, there is time and space to express the emotions without the pressure of resolving them. The lived experience provides the context in which parents can be at ease to be their authentic selves, challenging a common belief system wherein parents mask their emotions or demonstrate a façade of strength, regardless of their present emotional state. Other parents shared their perspectives on the importance of receiving and providing support from a peer rather than a professional without the lived experience:

> It made a world of difference because I'm not just talking to anybody, I'm talking to another mother who's going through those issues [...] So, they understand you. They have compassion for you that way. (Parent 6)

The parents' shared lived experience, genuine understanding of one another, and reciprocity contribute to the development of a relationship that is conducive to creating the foundation necessary for the resilience process of modifying family belief systems (see discussion).

4.3 | Subtheme: Listening, understanding, and responding to stories

Sharing one's story is about being heard. This is part of engaging in broader social discourses around what matters most to these families. A major part of the network, for parents both accessing and providing peer support, is creating a venue where parents can feel genuinely heard. As one parent participant explained, families sometimes feel they are not well understood by professionals and take extraordinary measures to demonstrate their needs:

> I used to take recordings of his ... of his injuring himself. Recordings of him hurting others or what goes on, and you know, photographs and tapes ... like, so that they believe me. (Parent 6)

That same parent reported feeling heard and understood by peers who supported her family to eventually access the care she had been seeking for years. She explained that looking back after finally getting the support, the extent of her needs is undeniably clear:

> [Now] he's got his caregivers 24/7 [...] So, he has a team looking after him where it was just me alone. One person doing what 8 or 10 people are doing now. So, because, no doubt, that has made all the difference in our lives, and this is what I was advocating for and I would like. I said, asking everybody, "this is the help I need." (Parent 6)

Parents seeking support from other parents may be able to be more vulnerable than when meeting with professionals. As one peer supporter described, they can feel at ease to express themselves in an "unguarded way" without fear of being misinterpreted or judged because "they're not coming to you for professional advice or professional guidance" but instead are seeking explicitly to connect with "another person that gets it" (Peer supporter 4) or someone who "had fought some of the same battles" (Parent 2). Sharing one's story also allows for opportunities for meaning-making for peers (see also Theme 3). One parent described sharing her experience as an emotionally challenging one, but ultimately saw it as an opportunity to support other families:

> They asked me if I would be interested in sharing my family journey [...] even though it's quite emotional [...] there's always the opportunity to help somebody else when you're sharing. (Peer supporter 8)

As several parents reported, there is indeed a need to share and hear these stories. This is how one parent described her need for a space to share her experience:

> I used to be crying because I was so dejected, and you know my health has been affected all these years

dealing with my son's struggles and issues. So obviously I was full of emotion, you know, and then where do I take all these feelings? (Parent 6)

Some parents also highlighted the deep relational connections that can be made through storytelling. One parent reflected on her experience of sharing her story with someone who had a similar family experience, reporting that "it was like a homecoming [...] like [meeting] a family I never knew I had" (Network coordinator 2).

Peers can provide informal emotional support that parents may not be able to receive from their partners, friends, or professionals. Several participants described part of their role as providing a space for holding emotions and receiving stories without necessarily leading to any sort of intervention:

> So when they start talking, I realize, oh, OK, gotcha, you don't have a lot of people talk to so and [they say,] "I'm rambling" and I say, "No, vent. Go. talk away. You need to do this because that's a big part of this. We need to talk. You need to get it out." (Peer supporter 5)

> [H]earing that somebody else has gone through that, [...] and that it took them a long time to figure out what they wanted to do about a problem, is helpful in its own regard [...] This isn't about necessarily directly solving a problem in the moment. (Peer supporter 4)

In these quotes, we also see a need for peers to be skilled at recognizing when parents are seeking support in problem-solving or identifying resources; needing to be heard and understood; or needing to hear the peer's story to identify potential alternate futures.

Peers must decode when and how to share their own stories and make space for multiple narratives of similar situations. One parent highlighted the importance of being cautious around the timing of sharing stories that do not support a positive outlook.

> If you're already in crisis and feeling hopeless, the last thing you need to hear is another resource parent saying that it's hopeless [...] [Instead] say that, "this is just my experience, so it may not be yours. You know, maybe other people have better experiences, but in my experience, this is what actually happened for me" and try not to generalize that in terms of "the entire system always works this way." (Peer supporter 4)

The same parent went on to explain her perspective that peers use their lived experience to drive their curiosity and provide emotional support in a way that normalizes a parent's experience but also acknowledge idiosyncrasies in their journey:

> You use your lived experience to be curious, not to say "I know exactly what you're going through," but you

say, "Well, this is where I was at at that point. I wonder if you're experiencing the same thing." (Peer supporter 4)

Receiving stories from other parents can be both emotionally taxing and beneficial to peers. Peers can benefit from receiving stories and seeing the impact of their support, which gives meaning to their own experience of raising a child with a neurodisability. For example, one parent related the stories she has heard back to her own family experience:

> The children are getting their early intervention that they need. They're at the right places. So, that makes me happy because I'm like, "I can't wait to see what this child is going to learn," like my own. (Peer supporter 5)

However, receiving the stories can also result in a "heaviness," which requires emotional work on the peer's behalf as noted by one participant:

> More often than I thought there are days where I'm like "OK, you know what? That was a really heavy, heavy day" [...] It can affect me and I'm not going to say negative, but just it can be very daunting [...] As a result of that I'm trying to teach myself to be able to kind of change that mindset. (Peer supporter 7)

So, while peer supporters report finding meaning out of the support that they offer, there are emotional consequences of being involved with these other families and receiving their stories. These stories may be in themselves emotionally charged. However, to provide genuine empathy, peers tend to reflect on their own family challenges, trauma and/or successes, thereby potentially increasing the intensity of the emotional experience when receiving stories from other parents (McCrossin et al., 2022).

4.4 | Theme 2: Navigating resources

The second theme demonstrates how peer support helps to facilitate navigation of resources by increasing access to external resources for the family, promoting internal resources of the parent, and through the network acting as a resource itself.

4.4.1 | Subtheme 1: Identifying and facilitating access to external resources

Facilitating access to resources requires peer supporters to have skills in hearing stories and providing empathy as a means of identifying and acknowledging family needs, as well as having some practical knowledge of existing community resources and skills in navigating

systems. Several participants reported on the expertise of peer support parents in this regard. Peer supporters know what questions to ask, hold knowledge about what meaningful services exist, and where to seek out these resources. Having lived through certain developmental phases of raising a child with a neurodisability, the network is full of knowledge of where to access resources on a provincial and regional basis. One peer supporter explained, "You know it's us parents, we know where to go" (Peer supporter 5). Another suggested that the network holds knowledge that other systems do not:

> I think the medical system and the teaching systems are stretched so thin that that kind of support just doesn't exist outside of something like this [peer support network]. The practical knowledge of problem-solving how to navigate the systems [...] that knowledge exists within all the parents and so we need to capture it and connect people so that that knowledge is shared. (Peer supporter 4)

Furthermore, being a part of the network allows for an expanded knowledge of supports and increased capacity to navigate health and social care systems. One parent commented on her experience becoming a peer supporter: "it's allowed me to learn more, especially as an immigrant and a newcomer to Canada to learn more about the social systems" (Peer supporter 8). Furthermore, this sort of peer networking across the province has supported families to identify pathways to accessing services and leveraging precedence for enacting specific governmental policies across various districts.

4.4.2 | Subtheme 2: The peer support network as a resource

In addition to connecting families to external resources in the community, the peer support network also operates as a resource itself through connecting parents to peers to share stories and provide informal emotional support. Peers also provide practical support such as joining parents in meetings with professionals in the health, social, and education sectors. The structural mechanisms of the network allow for linkages to be made between parents and resources. Without this network being in place, those linkages would not be possible.

Participants explained that since the onset of the COVID-19 pandemic, the expansion of online platforms used by the network have facilitated increased access for families to connect with others with similar experiences. This is particularly the case for families that live in remote communities but also for families of children with particularly rare conditions or in unique situations relative to their geographic communities. The network facilitates connections between these families through regular group video conferencing and through peer matching.

Participants noted that being part of the network provided practical support including: identifying meaningful resources they had not previously been aware of having a peer present for meetings or being copied on emails and using a sort of "case-law" approach to advocating for certain resources on the basis of those resources being available in other districts. One mother described how she solicited the presence of peer supporters and within weeks she received the support she had been advocating for over several years:

> And those other moms starting intervening, and you know, they started participating in my meetings with [social services]. I used to request them. Please come join the meetings. Please talk about my situation because I think if they are not believing me, at least they believe you because it's a professional organization, right? So then, you won't believe it, and I'm not exaggerating here, in a few weeks my situation changed …. (Parent 6)

This is a powerful example of how the peer network can lead to meaningful change to families, years after navigating systems and services alone.

4.4.3 | Subtheme 3: Activating and discovering internal resources

The peer support network serves as a venue for families to discover their internal resources and strengths. Parents noted that over the course of the COVID-19 pandemic, families of children with disabilities have experienced significant challenges, such as a drastic drop in respite and other supports. However, participants also highlighted that these same families are used to being flexible and navigating difficult situations. For example, the resourcefulness of parents is clearly demonstrated in how they adapted quickly to new ways of connecting online.

The network is also explicitly designed to highlight the nonprofessional expertise of parents. In the peer support role, a parent's expertise lies in their lived experience. Some participants expressed feelings of insecurity or hesitancy to provide peer support because they do not see themselves as experts.

> [S]ometimes I don't have that confidence. I'm like, oh man, I *might* be able to help this person […] You know what? I'll try. Like, let me talk to the person, let me see what the situation is and see if I'm able to or not, and if we can't, I'll just redirect them to the person who does know […] And it ends up working. I'm kind of winging it. (Peer supporter 5)

> I could provide some commonsense advice, but it may not be in the context of exactly what they were facing. (Peer supporter 4)

Despite the sometimes-wavering confidence, the experience of peers that were interviewed in this study suggested that by improvising, moving slowly, and seeking support from the network, peers can build confidence in their skills. One peer supporter described how her level of confidence improved with recognition of her expertise by the network:

> You know they kind of give you that confidence, that kind of feeling. (Peer supporter 5)

By reframing the experience of peer supporters as nonprofessionals that are experts at navigating difficult situations, peers develop internal resources they can pass on to others.

4.5 | Theme 3: Negotiating resources and engaging in social discourses

The third and final theme demonstrates how peer support helps parents to negotiate for meaningful resources and participate in social discourses that contribute to a positive outlook in relation to desired outcomes for families. This participation goes beyond motivations at the individual or family level to represent making a difference at the community or societal level.

Several parents described the importance of contributing to supporting other parents and changing the current system of supports for families as an opportunity to make meaning out of their own experience. One peer supporter noted that, "I would like some meaningful outcomes to the struggles. I would like to make it easier for other families down the road" (Peer supporter 6). Another peer supporter described the importance and role of the collective knowledge of parents:

> And what we're doing is we're sharing our knowledge together, we're saying, these are the issues that we face. This is what we need for our loved ones and let's start defining this and collecting this information together because as a whole we're able to maybe down the road communicate these needs or help influence the building of a system that's better. (Peer supporter 4)

Being a part of the network permits parents to advocate not only for their needs, but to negotiate for effective delivery of support for all families:

> Ensuring the agencies that are paid to support us are doing that in an effective way and looking at models of care that are … that really would work better from a family-centred perspective to meet not only the needs of the disabled person but the whole family. (Peer supporter 4)

I'm always thinking about the bigger picture specifically for me. I think that the stuff I do fulfills a need in me to improve the system [...] that has formed out of having my son. (Peer supporter 6)

Through the network and collecting of parents' voices, peer supporters can contribute to meaningful engagement in social discourses around disability policy and supports leading to change in the community. One network coordinator described how engagement with community committees and sharing the concerns of parents led to tangible changes for families: "[Through] a lot of committee reports and a lot of committee time and constantly voicing what families are seeing [...] they heard us and made that change ..." (Network coordinator 7). However, participants noted that parents are not always aware of the existence of resources or a vision of what their future could look like for their family. That same coordinator explained that helping families to identify the resources they need and develop this vision is part of the work of the network:

> When I speak to families ... I like to excite them about the possibilities and ... What would their dream be? [...] I like to help them dream big. (Network coordinator 7)

This network coordinator sees part of her role as supporting families to think differently and get unstuck; to identify their desired outcomes and communicate this with political powers to drive tangible change.

One parent explained that being a peer supporter allows her to envision a different future for her child and her family through witnessing the experience of other families. While initially worrying about her child's future, through learning about another family's experience she now looks forward to the future that she envisions for her child.

> My worry was that will he be staying at home with me? Will he be living with me? Will I have to always support him? Will he– Can he have a job? Can he go to college? [...] So this person [that I met through the network] has his own home, his own funding, and he has staff members taking care of him. And his parents, they get to see him on the weekend and have fun with him. And I'm like, "oh I can't wait for my son to do that." So, my son would have his own life, his own workers, his own job, and I get to be the fun parent on the weekend. So, I look forward to that. (Peer supporter 5)

This parent's experience demonstrates how being involved with peers creates space for meaning making through exposure to and involvement in alternate belief systems and family narratives. In receiving this family's story, the peer supporter is able to generate a new representation of her child's future. Several parents also spoke about the meaning they make from their own experiences and struggles through helping others:

> I love to give out as much information I can to help another parent out because I understand. I get it. (Peer supporter 5)

> It brings me great, great joy to know that in my time of need or when I really was having hard time, the relief and the sense of belonging was, oh you know, "I'm not alone." There's other people there that understand what I'm going through and then it makes me remember back to all that I went through ... and I think that's why I'm so passionate about being involved with [the network] as a resource parent and as a regional network coordinator. It's important, to me to let other families know that they're not alone. (Network coordinator 3)

These excerpts highlight how parents can be motivated by the discomfort in seeing others struggle and the desire to create a community where parents have the information they need to support their families and at the same time feel connected to a community.

5 | DISCUSSION

The present study adds further evidence to previous research findings reporting that peer support for families of children with neurodisabilities operates through shared lived experience (Chakraborti et al., 2021; Shilling et al., 2013, 2015a). Previous studies also demonstrated that parent-to-parent support provides fertile ground for parents and peers to develop new, positive visions for the future and opportunities for individuals to thrive (Bray et al., 2017). Like Dodds and Walch (2022), we view peer support through a family resilience lens. Therefore, we have organized our findings to demonstrate how the relationships and underlying processes of peer support can be understood within a family resilience framework. Based on these findings and several family resilience concepts and frameworks, we propose an integrative family resilience theoretical model (Figure 1) that maps out pathways through which peer support can facilitate preferred outcomes for parents, children, and whole families.

The peer support network in the context of this study offered peer support at the level of the parent. We argue that in this context a family resilience model is the more useful than one of individual resilience. While the participants were all adult women, they were being interviewed in their roles as parents. The underlying processes were therefore not limited to individual experiences but instead were focused on parenting processes that affect the whole family system (Masten & Palmer, 2019). In our model, the general structure of the family resilience components is borrowed from McCubbin and Patterson's (1983) Double ABCX model with influences of concepts elaborated on by Ungar (2010) and Walsh (2016). We identify several processes through which peers contribute to resilience in families, namely, the themes and subthemes that allow for the modification of belief systems and the navigation and negotiation of access to
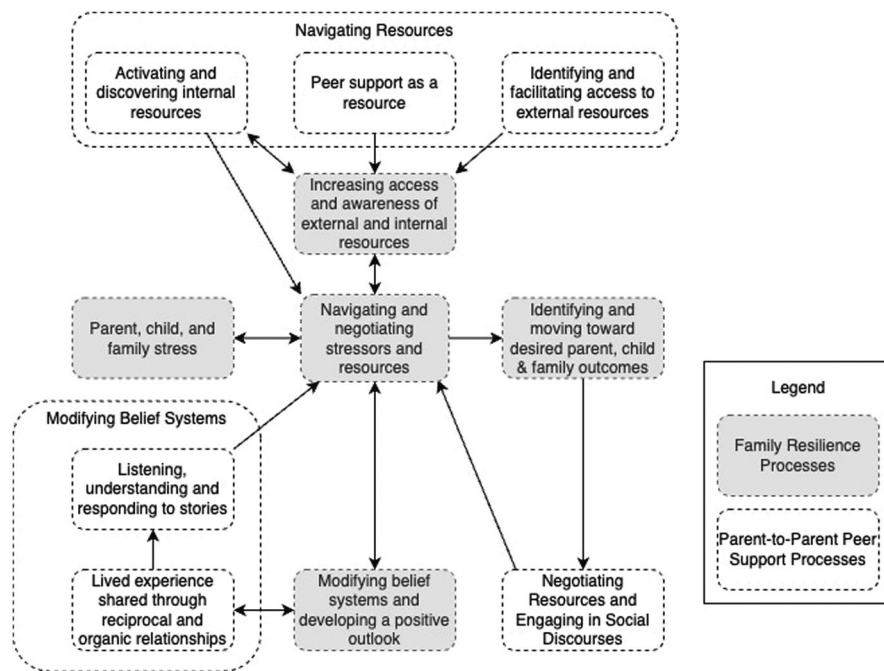
meaningful resources. These processes represent what peers do by leveraging the qualities and strengths embedded in the reciprocal relationships and shared lived experiences. Our model demonstrates how each of these peer support processes intersect with components of family resilience theory and in turn inform our understanding of how processes of resilience operate and are maintained.

Our results suggest that lived experience may serve to shift family belief systems, organizational patterns, and communication in families involved in the peer support network. Walsh's (2016) definition of family belief systems refers to several processes including making meaning from adversity and developing a bias toward a positive outlook. Both processes were evident in the experiences of the parents receiving peer support in our study. Peers spoke about making meaning from their own adversity by helping and supporting other parents to learn from their struggles and other experiences. Participants also spoke about feeling anxious, worried, and even hopeless about the future. Through a reduction in isolation and developing authentic, organic relationships, parents are able to develop alternative, realistic, and more positive outlooks.

Walsh's (2016) framework was intended to be applied to family systems: however, we can apply some of these processes to other systems. For example, organizational processes (one of Walsh's three key processes) refer to flexibility, connectedness, and mobilization of social and economic resources (Walsh, 2016). Considering these processes in the context of the peer support network, we can see that parents demonstrate flexibility through meeting individual needs; connectedness through reciprocal support; and mobilization of resources through facilitating access to internal parental resources as well as external ones in the community including the network itself. Similarly, communication processes in the network serve to support clarity in information and messaging between peers

as well as between parents and other systems (e.g., in meetings with health, social, and education sector professionals). The network also facilitates the resilience process of emotional expression whereby parents are afforded the space to share authentic emotions without judgement or agendas. In particular, the lived experience and reciprocal nature of peer relationships were identified as key facilitators of this process. Furthermore, problem-solving processes allow for empowered decision making in relation to navigating crises as well as preparing for the future.

Our model also incorporates the notion that resilience involves navigating and negotiating for resources to be delivered in meaningful ways (Ungar, 2010). Peer supporters in our study helped parents navigate resources through identifying resources and pathways to access them. Furthermore, the resources identified by peers were reported to be highly relevant to families and the pathways to accessing them were successful, in part due to the lived experience of the peer supporter (e.g., the peer had accessed those resources in the past) and/or the wider experience of the parents in network. Peers also supported other parents to negotiate for resources and to take an active stance in developing a vision for their preferred outcomes. This occurred through sharing stories, joining families on their journey, and mobilizing their collective voices to advocate for systemic change.

Lastly, our peer support and resilience model includes bidirectional and transactional processes. The peer supporters providing support are also in a position to receive it, whether that be from the same relationship, a network coordinator, or the broader network of peers. Furthermore, while hearing stories of other families, we found evidence that changes in belief systems were not limited to families receiving support but occurred in peers as well. The reciprocal nature of the peer-to-peer relationship was described by participants as an

essential component of peer support and we argue here that it is also necessary in the maintenance of processes of resilience in our model.

5.1 | Study limitations

Only women were interviewed for this study and perspectives from others in their families were not explored. A gap remains in understanding how family units interact within the context of peer support. For example, we did not ask participants to what extent partners and children had access to the peer network or were even aware of its existence. Additionally, because this study involved a reflexive thematic analysis, the interpretation is necessarily driven by the authors' personal and professional experiences and biases at a given point in time. The interpretations of the data are subject to an evolving understanding of the experience of parents in this peer support network.

5.2 | Conclusions

Our findings suggest that those building or implementing peer support programs should intentionally adopt a family resilience lens in their training and in their representation of these programs when communicating to others the complex work that they do. The peer support and family resilience model in this article demonstrates how parent-to-parent networks can modify family belief systems, help navigate complex networks of care, and support negotiation for access to meaningful resources.

Our study also identified how peer support can be understood in the context of family resilience theory and how reciprocity in peer support maintains processes of resilience. We believe this will be useful in building hypotheses around how interventions at the parent-level can cascade to the level of the family and broader community. Future studies should explore caregiver perspectives on how peer support impacts their whole family unit.

CONFLICT OF INTEREST
We have no known conflicts of interest to disclose.

ETHICS STATEMENT
The study was approved by the Research Ethics Board at McGill University prior to interviews being conducted.

PARTICIPANT CONSENT
Informed consent was obtained from all participants.

DATA AVAILABILITY STATEMENT
The data that support the findings of this study are available from the corresponding author upon reasonable request.

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