“They may cry, they may get angry, they may not say the right thing”: A Case Study Examining the Role of Peer Support When Navigating Services for Children with Neurodisabilities.

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Abstract (200 words)

Background: The term ‘navigation’ refers to a service that aims to facilitate interactions between service users, families, and/or service providers with the ultimate goal of improving access to care, and often includes some provision of emotional support. Peer support for parents as a form of navigation for families of children with neurodisabilities likely facilitates family resilience through their shared lived experience. However, there is little research available describing the experience of the key stakeholders engaged in this type of peer support.

Methods: Through thematic analysis of qualitative interviews, the present case study examined the experience of three mothers of children with neurodisabilities (a parent, a volunteer peer supporter, and a network coordinator) engaged in parent-to-parent peer navigation support.

Results: This case contributes to evidence that peer support serves a similar purpose to that of other forms of navigation support by increasing access to instrumental and emotional resources but differs in that it operates through shared lived experience. A unique finding was that the peer supporter used self-reflection and emotional expression in order to simultaneously provide empathy and bridge communication between the parent and service providers. Benefits and emotional challenges to providing peer support were reported. The network coordinator played a dual role, providing support to both the parent and peer supporter.

Conclusions: Findings suggest that peer support does not replace professional support but instead plays a complementary role in helping clients feel understood and access services that are meaningful to them. Peer supporters can benefit from developing navigation skills, however their role demands significant self-reflection and emotional investment. An additional layer of support to care for peer supporters may contribute to the sustainability of peer support networks.

Keywords: navigation, neurodisability, peer support, family resilience, volunteering

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Introduction (500 words)

Children living with neurodisabilities such as Autism Spectrum Disorder, Cerebral Palsy, or Down Syndrome (Morris et al., 2013) often require a range of health and social services and informal support across their lifetime. Such services are often siloed and untailored to specific needs of each family, which creates a need for support in navigating meaningful resources (Brown et al., 2014; Lindeke et al., 2002; Luke et al., 2018).

Families may be expected to navigate and coordinate services whether or not they have the skills or capacity to do so, resulting in poor uptake of the services that may appear readily available. In another scenario, families may be able to navigate services but struggle to negotiate for them to be delivered in a meaningful and culturally appropriate manner. These two concepts and skillsets of *navigation* and *negotiation* are key characteristics of many navigation services but also important aspects of resilience (i.e., doing well in the face of adversity) (Ungar, 2010). To emphasize this key point: individuals and families need not only an abundance of resources in order to thrive in the face of hardship, but they also need the skills and knowledge to access those resources and to advocate that they be delivered in a fashion that adequately meets their needs (Ungar, 2010).

The use of the term ‘navigation’ in healthcare has its roots in cancer care in the 1990s (Freeman, 2012). While the term lacks a singular definition, generally, navigation refers to a service, program, or provider that aims to facilitate interactions between service users, families, and/or service providers with the ultimate goal of improving access to care (Carter et al., 2017; Luke et al., 2018). Navigation also often includes a component of emotional support to the service user and/or family (Luke et al., 2018). Formal navigation services may be delivered by a range of professionals, namely social workers and nurses, or by lay persons such as family members or volunteers (Carter et al., 2017; Luke et al., 2018). Navigation includes empowering families to shift their perception or belief systems around stressors in a manner that allows for them to make best use of the resources available to them, improve their perception of their capacity to cope, and ultimately adapt to a new normal. In addition to finding new resources, navigation also involves maintaining or reestablishing access to existing resources both internal and external to the family system as connections to these supports may have been weakened or cut-off following a crisis.

Peer support, as a form of navigation, likely operates through shared lived experience (Shilling et al., 2015). Emotional support offered by peers is facilitated by their capacity to draw on shared lived experience to provide genuine empathy. Perceptions and family belief systems can be influenced by peers sharing their stories and providing alternative narratives to parents that may be feeling stuck or hopeless (Manning et al., 2011). Moreover, peers can attune to other parents through their shared lived experience to identify and facilitate access to resources that are likely to be highly meaningful to families.

The present case study is the first stage of an effort to provide a rich description of the Family Support Program coordinated by the Family Support Institute of British Columbia (FSI), a Canadian volunteer-based peer support and navigation initiative. Using qualitative case study methodology (Yin, 2018) with multi-level input, this article describes the experience of taking part in a parent-to-parent network from the perspective of a service user (parent), volunteer parent navigators (Resource Parents, RPs), and staff coordinators (Regional Network Coordinators, RNCs)(see Supplementary file for a description of the service).

Materials and Methods

The present case study followed a single descriptive instrumental case study design using an embedded unit (Figure 1) (Baxter & Jack, 2008; Yin, 2018). Case study research is best suited for studies where the researcher seeks to understand a phenomenon in depth and within a real-life context and when the boundaries between the phenomenon and context are unclear (Yin, 2018). As such, case study was chosen as the methodology because it provides an opportunity to develop a rich description of a family-based peer navigation service as a phenomenon within the real-life context of a particular case (i.e., the FSI Family Support Program). Studying peer navigation outside of the context of the program would not be possible given that the navigation operates within a network of volunteers and staff. A multiple case study approach was excluded from consideration given the relative absence of comparable cases. This study is *instrumental* in that the context of the case plays a supportive role in facilitating a deeper understanding of peer service navigation as a phenomenon.

The present study could also be described as a process evaluation case study (Yin, 2018), whereby the process of implementing the initiative (i.e., the Family Support Program) is the focus of the case, rather than the objective success of the initiative. Compared with other methods of evaluation such as experiments and quasi-experiments, the case study is able to capture the complexity of the case and changes over time, attend fully to the context of the case, and explain how the intervention or initiative works (Yin, 2018). As such, interview guidelines were designed to develop a better understanding of roles and relationships between key stakeholders (i.e., parents, RPs, RNCs) within the Family Support Program in order to describe how they contribute to and experience the peer navigation initiative.

Ethics Statement

Ethics for this pilot project was obtained through the McGill University Research Ethics Board. Informed consent with each participant was obtained by the author (JM) at the beginning of each interview. Participants had the right to withdraw from the study and to decline to answer questions if they felt uncomfortable answering. Participants consented to anonymized data from the interviews being used for the purpose of furthering research on the concept of navigation and to provide feedback to FSI to improve the Family Support Program. The first, fourth and fifth authors (JM, WM, LL) have affiliation with FSI outside of the context of research and declare no conflicts of interest. Authors affiliated with FSI were not given access to raw data collected during the interview process.

Recruitment

Recruitment for this pilot project was supported by management at FSI and consisted of three participants: a parent, an RP, and an RNC, all from a single, rural region in western Canada. The sample of participants was an embedded unit within the larger Family Support Program. All participants knew one another and were mothers of a child with a neurodisability.

The RP and the RNC worked closely together to provide coordinated and direct support to the parent. The participants were chosen specifically by FSI as key informants because they were known to have worked well together and were likely to be open and willing to participate in the study. For the purposes of a case study pilot, this type of convenience sampling is encouraged to facilitate ease and comprehensiveness of data collection (Yin, 2018).

Interview Procedure

The primary source of data was interviews via video conference software. Demographic information was collected verbally from each participant by survey during the interview.

Interviews lasted between 1 and 2 hours. The first author (JM) was the sole interviewer. FSI's webpage for their Family Support Program (FSI of BC, 2020) as well as onboarding documents were included as sources of data for thematic analysis and triangulation to support trustworthiness of the findings. Lastly, memos and fieldnotes were reviewed to support the identification of themes for analysis and contribute to the rigor of the analytic process.

Analysis

Interviews were transcribed and coded using Dedoose mixed methods software (Salmona et al., 2020). Codes were compared and adjusted through an interrater exercise with a student colleague. Data gathered through the interviews and demographic survey were triangulated with an analysis of data provided by FSI in terms of their website as well as onboarding and other relevant documents for clients, volunteers, and staff. The results of this study will contribute to the trustworthiness and rigor of a larger project currently underway, which includes an expansion of participants as well as an online survey destined to a wider participant base.

Results

Drawing on Shared Lived Experience to Support Parents

The following sections will describe the type of support offered by the RP and RNC and how the support was experienced by the participants.

Navigating systems and accessing resources. From the perspective of the parent-client, the support from the RP and RNC were overlapping with both directly providing interventions. The experience of the support was deemed overwhelmingly positive. Consistent with commonly described tasks of navigators, the RP and RNC provide practical support by guiding the parents through co-developing plans, connecting to resources, and attending meetings with parents. The parent participant noted that the RP and RNC knew about resources she had not heard of, and they knew how to access them. Connecting to resources and navigating through systems is a skill that parents develop with lived experience.

All three participants reported extensive collaboration with various community and government organizations including advocacy groups, funders, housing supports, care coordinators, and ASD networks. The parent participant indicated that the support was not just for her child but supported her directly as a parent as well.

The RP and RNC participants reported appreciation for supports offered by FSIBC in order to carry out their role in navigating systems and resources, highlighting tools like the transition timeline, webinars, the RP network Facebook group, as well as collaboration with colleagues for training and mentorship.

[Placeholder for Box 1]

Teaching parents how to navigate systems: orientation. Parents of children with diverse abilities find themselves in survival mode, making it difficult to know who to go to, what to ask for, or where to start to access support. The participants commented on how parents can be supported by their peers through learning how to navigate the steps and systems to get the support they need. While the RP and RNC were at times available as a supportive presence when accessing resources, it is worth noting that they do not view advocacy as a part of their role. Instead, they shared their own stories and those of others they knew through their networks who experienced similar circumstances, thereby sharing knowledge of relevant resources available as well as pathways to successfully access them. Related to this, the RP noted that she was able to build on knowledge gained through each experience she had volunteering with families, which allowed her to better support other families including her own (see below for more discussion of the benefits, and challenges, of being an RP).

[Placeholder for Box 2]

Emotional processing at meetings with professionals. The task of attending meetings with parents, such as those with government agencies responsible for providing care, was commonly highlighted as an important part of the roles of the RP and RNC. The RP and RNC developed expertise in knowing what questions might be asked in these meetings, who would be there, what services could be accessed, and how to behave to increase the odds of getting the support requested (e.g., providing evidence of exhausting all currently available resources).

The RP participant recounted her experience of becoming emotional in a meeting and how it connected to a reflection of her own family's experience. The RNC normalized the RP's expression of emotions in meetings with government agencies. She also indicated that a need to go against the prevailing culture of such meetings and make room for parents' emotions, including those of RPs. The emotional challenges of being an RP are discussed in greater detail below.

[Placeholder for Box 3]

Informal social and emotional support. The RP and RNC provided informal and emotional support by tapping into their lived experience and recognizing the expertise of parents. The participants described informal supports as meeting for coffee, giving space for parents to express themselves, and intentionally taking a non-professional stance. As a person with both a professional identity and lived experience as a parent, the RNC noted the need to be flexible when offering support as a parent versus that of a professional. Informal emotional support was provided by connecting as parents with similar concerns and being present without an agenda to assess or gather information.

[Placeholder for Box 4]

Sharing lived experience. All participants perceived parental expertise to be highly valuable and reported that support from parents with lived experience is distinct relative to professional support. The parent reported she felt genuinely understood knowing that both the RP and RNC had an experience of parenting similar to hers. The RNC noted that the support person does not need to know exactly what the parent is experiencing but can tune into their own experience to demonstrate empathy and validate their emotions.

[Placeholder for Box 5]

Revealing Emotional Complexity: The Benefits and Challenges of Providing Peer Support

These remaining sections described the benefits and challenges of providing peer support.

Emotional weight of being a peer supporter. The participants all reported perspectives on the challenges of being or becoming an RP. The RP described how working with other families made her reflect on the circumstances of her own family. Furthermore, the type of requests for support the RP received were emotionally heavy. However, she noted that the network was responsive to her needs by respecting self-set limitations around taking on new families to support.

Not all parents are in a position to become an RP. In relation to the recruitment of new RPs, the RNC noted the importance of being able to reflect on one's own personal experience and how it relates to that of the parent being supported. However, the RP must also be emotionally available so as to not project their experience on others. The parent participant was clear that she could not envision taking on the role of an RP, recognizing the toll of being a parent of a child with a neurodisability and the emotional leftovers that would impede her from having the desire to find herself navigating those systems again.

[Placeholder for Box 6]

Benefit to the RP. Both the RP and RNC reported the benefits of volunteering as an RP. The primary benefit reported was gaining valuable knowledge and skills from the experiences in supporting families. The RP was able to directly use skills, knowledge, and relationships she built in the context of volunteering in order to then support her own family. The RNC facilitated this benefit through being available to provide the RP with instrumental and emotional support.

[Placeholder for Box 7]

Discussion (<u>1000 words</u>)

In this case study, non-professional peer support was valued by the parents (mothers) receiving and providing the support. The navigation support received through peers was distinct from that of professionals in that it operated through shared lived experience. When peer supporters share their story, they facilitate access to new or existing resources by providing a vision for how these supports could be accessed and the possible benefit they could make in the life of the family. Sharing their experience also creates opportunities for shifting family belief systems in a manner that permits the parent to positively appraise the balance between the family stressors and available resources. When parents know that their peer supporters have had similar experiences as parents, they feel they can be well understood. While feeling understood is a potential benefit to parents on its own, there are other cascading benefits to this understanding. For example, when resources and pathways for managing stressors are shared through peer support, there exists a mutual understanding that those resources and pathways will be meaningful and attainable for someone in the parent's position. This process has the potential to increase access to services and improve outcomes for families.

Indeed, shared lived experience can allow for a profound level of empathy for others. Professionals may be knowledgeable and sensitive to the needs of these families, however without lived experience their empathic capacity may be limited. A peer supporter, however, can reflect on their own experiences to develop a sense of what the parent might be feeling.

RPs can play a unique role of conveying emotions on behalf of the parents they support. Parents behave and express themselves differently in front of professionals compared to peers. Parents of children with neurodisabilities often feel the need to maintain the appearance of being strong in front of professionals which may impede the communication of emotions they experience. These emotions carry important feedback for professionals that can change the course of the services they provide to respond to the needs of families. Peers can tune in to the experience of the parent and express those emotions, effectively acting as a conduit through which the parent's experience and needs can be expressed, particularly in moments of high stress. For example, the RP attended a meeting with a service provider. The parent was unable to convey the distress she was experiencing in relation to the outcomes of the meeting. The RP tuned into the emotional experience in a manner that may not have been perceived by the service provider. By expressing the emotion, the RP drew attention to the unmet needs of the parent. Even skilled and well-meaning professionals are at risk of overlooking or misinterpreting these emotional experiences. While the expression of intense emotion is often not a part of the culture embedded in meetings with professionals, as noted by the RNC, peer supporters are not bound by this framework thereby sharing what might be uncomfortable or otherwise unsaid. The RP and RNC saw the RPs emotional expression as a powerful message of the human impact of discussions that parents have with health and social care professionals. A peer supporter's presence can contribute valuable data to meetings such as this, thereby increasing the odds that the parent will be well understood, and appropriate and meaningful resources can be made available.

There is significant emotional complexity to the RP’s role. Peer support requires extensive self-reflection. Experiencing this deep sense of empathy and expressing it can be burdensome on the emotional experience of peer supporters. The parent participant could not imagine herself becoming an RP, suggesting that the weight of her own experience of a parent would not be something she would want to amplify through regular self-reflection. The RP reported regularly reflecting on her own family's experience and trajectory, giving rise to confronting emotional experiences. These emotional challenges were managed, in part, through shared lived experience. The RP received emotional and instrumental support from the RNC who understood challenges she was facing. The RP relied on debriefing and setting boundaries to process her experience and care for herself. However, while self-reflection and foreshadowing brought about heavy emotions, the RP also reported these processes as beneficial.

An additional layer of support in the peer-to-peer relationship may facilitate access to benefits of being an RP. The RNC provided knowledge, emotional validation, mentorship, and helped to share the load of direct navigation support to the parent participant. Moreover, the RNC was available to provide informal support as a witness to the RP’s “foreshadowing” experience. With all participants being parents experiencing parallel processes, findings are indicative of a circular relationship between the parent, RP, and RNC, rather than one that is hierarchical. In this case, the RP benefited from honing her skills and knowledge in navigating systems that were meaningful to her family circumstances. The provision of peer support was not seen by participants as selfless volunteerism, but rather as a process of reciprocal benefit. Both the parent and the RP benefitted from the relationship. The additional layer of support provided by the RNC to this unit of peer support may have, in part, facilitated this benefit. The RP was able to receive support from the RNC in terms of reassurance, information relevant to navigating systems, and debriefing particularly emotionally challenging moments.

In this case study, peer support differed significantly from professional supports. First, the relationships were developed in an explicitly non-professional and non-hierarchical fashion. The shared lived experience that bound these three participants together facilitated empathy and understanding that could be leveraged to bridge communication with service providers and increase access to resources for the parent and her family. However, much like clinical supervision for professional health and social care providers, an additional layer of support is likely to protect the well-being of the peer supporter and facilitate the benefits of this role.

Limitations

There were a number of limitations of the study. While pilot case studies are not intended to be generalizable, it should still be noted that the experience in other regions and with other parents, RPs, and RNCs, as well as other peer support networks, could be significantly different. While there may be similarities across family needs, families are all unique. As such, the manner in which navigation supports are implemented may vary widely. Furthermore, the availability of resources to match a family's needs could have an impact on how this model of navigation works. Additionally, while the onboarding documents provided by FSI indicate an awareness of the importance of attending meetings, the mechanisms around the RP's emotional process during meetings may not be something shared within other embedded units.

Future Research

Future efforts to describe and understand the experience and stories of key stakeholders in peer navigation programs can help in the uptake, modification, and future design of navigation services for families of children living with neurodisabilities. While the literature suggests that peer support functions via shared lived experience, to the authors' knowledge theory bridging peer support for these families and family resilience has not been explored. Such connections could provide a framework for greater understanding of the function and value of peer support for families and service providers.

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Key Messages

People with disabilities and their families: Peer supporters can help you learn about what resources might be useful to your family, how to access them, and where to start to get support. They can also be someone to talk to that understands what you and your family are experiencing.

Professionals: Peer support is a valuable resource for parents and families that can facilitate meaningful access to services.

Policy makers: Peer support is not a replacement for professional support. Instead it can complement the support from professionals and facilitate access to resources, thereby potentially improving the outcomes for families and communities.

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Figures

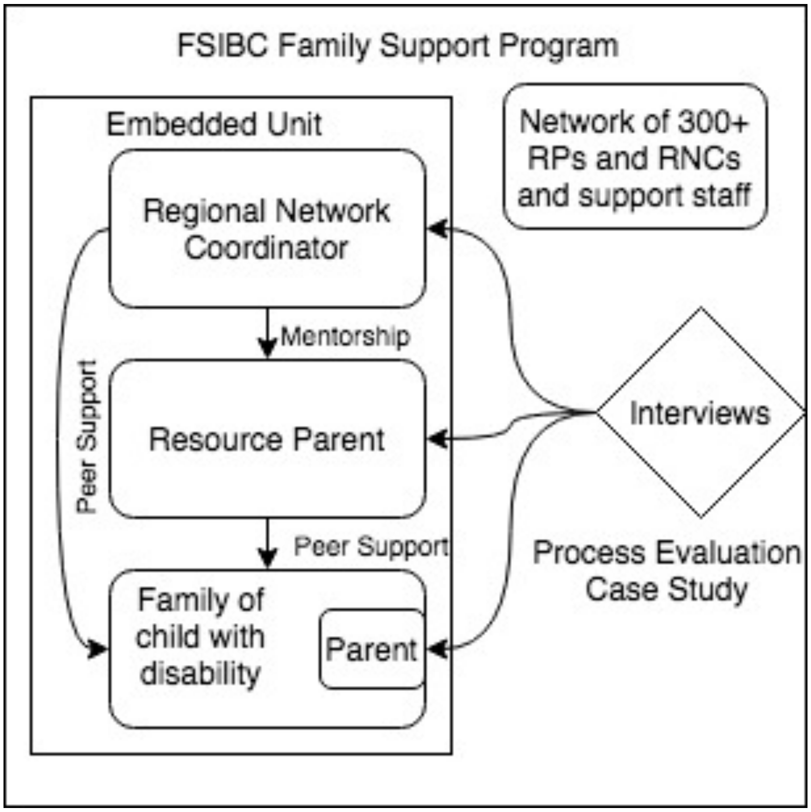

Figure 1. *Case study design with embedded unit.*

Extracts from Interviews

Box 1. **Navigating systems and accessing resources.**

> "[A]s a family member that has their son or daughter with a diverse ability you live in systems. So, you become a bit of a ninja navigator." (RNC).
>
> "[The RNC] went [to a mental health intake appointment] with me. She's kind of always chill and relax and it's what I needed… I start to get more relaxed and more alive" (Parent).

Box 2. **Teaching parents how to navigate systems: orientation.**

> "And one day we [were] at the coffee group and we [told] them that we are just done. Done, done. Don't know what to do next […] [T]hey [the RP and RNC] have knowledge. They know where to start and know people. They have connections." (Parent).

Box. 3. **Emotional processing at meetings with professionals.**

> “I was in, like, tears in that meeting, and, like, I'm supposed to be there to support parents, right? So, you know, I left it and I was so emotionally drained from it. I phoned the regional coordinator and I was like, I'm exhausted from that meeting, right? […] I think part of it was because I knew that was what we are going to go through with our son. So, I think there might have been some foreshadowing there.” (RP).
>
> “I guess the wild card that you're dealing with always when you're dealing with volunteers and parents is […] you don't have control over how they're going to react all the time. They may cry, they may get angry, they may not say the right thing. They're not professionals, right? They’re family members. They’re… they’re different. So, you and I might go into a meeting and that would be our inside voice, we would never say that. But a family member might […] call you out on that, right? […] And then all of a sudden… people get uncomfortable with that, right? Because that's not the culture of attending meetings. That’s not how we behave.” (RNC).

Box 4. **Informal and emotional support.**

> “[I]t’s that lived experience which is very different […] I can say […] as a navigator with my professional hat on versus my parent hat, it is very different […] I think you can just give families the space that they need to just kind of digest stuff. You're not just checking off boxes […] It's a journey. You may need help today or some support and then you don't need it for another two years and then you hit a wall or– but it's that social emotional support, too, that professionals can't really give you. Right? I mean they can't be everything to everybody, right?” (RNC).

Box 5. **Sharing lived experience.**

> "They [are] in the same boat. They know exactly what we're going through […] [O]ther people with normal kids, they think they know and they understand but they never live like that 24/7." (Parent).
>
> "So, I think it helps me in my own work too– to know that other families know I'm an Autism parent. They know I get it. You know, I don't live in a perfect world. Um, so days are tough." (RP).

Box 6. **Emotional weight of being a peer supporter.**

> "[W]hen I first started this with the first family, I was like, this could be me 3 years from now, right? And I remember saying that to the family, right? And the mom would– and you know because there's stigma involved with giving up your child and stuff and I remember saying, you know what? This might be me. This could happen to any of us, right?" (RP).
>
> "I think that my own personal life has kind of sorted itself out a bit. At the point like, in the summer if anyone asks anything more of me, I was just going to break, right? So, now I think I've gotten to the point where, yeah, I've sort of filled up my bucket again so to speak…" (RP).
>
> "They're always the right fit. Families are the fit. They are who we are. Sometimes it's just not the right time for you to do this. Because you just have some unpacking to do or you need to settle down in your anger. I don't want families going into meetings where, you know […] of course your own stuff is going to come into it. Absolutely. You're not going to be able to separate that, but […] how do you bring your own experience in with […] honouring the family that you're supporting. You have to learn how to do that." (RNC)
>
> "I just don't want to be in that anymore. Yeah, I know it's too much even if I'm done. I just want to relax and have normal life." (Parent on her decision to not become an RP).

Box 7. **Benefit to the RP.**

> "… I didn't really know the ins-and-outs of the system and now I know it a lot better and I feel comfortable enough to advocate for ourselves." (RP).
>
> "[T]hat experience supported her [the RP]. Like, that's the ripple effect of this peer support […] [S]he has a great skillset and she just needed a little bit of information or she needed reassurance or she just needed to, you know, call me and cry on the phone and just cry and just say, 'hey I'm overwhelmed I can't… I don't even know how this family is doing it' […] And so just being there through that journey and then to come out with such a… such a successful outcome for your family […] I mean it kind of sounds strange when you say success but they were able to able to advocate for themselves to get the support that they needed and more importantly for their son and for their family." (RNC).

Supplementary File: Case Description

The Family Support Institute of British Columbia (FSI) was established in 1985 and has developed into a key resource for families with children living with a disability. The Family Support Program is a central component of the organization which provides a no-cost peer support and service navigation to any family or individual living with a disability. This support is provided by nearly 300 Resource Parents (RPs) across the province who share experience and expertise, and guide and support families in their own communities. Tasks of RPs and RFMs may include attending meetings and taking notes, increasing awareness of FSI through presentations, and providing an attentive and non-judgmental ear to families. All RPs have lived experience caring for a child or other family member with a disability. Notably, FSI is not an advocacy group but rather a charitable organization that aims to "strengthen, connect, and build community resources with families of people with disabilities in BC". In line with a resilience theoretical framework, the organization's mission, vision, and philosophy emphasize the value of expertise of parents and families and the capacities of families to negotiate for their needs to be met when supported with the right information and adequate resources.

Recently, 12 Regional Network Coordinators (RNCs) were hired in regions across the province of British Columbia to support this network of volunteer RPs. RNCs support RPs in their volunteer work through mentorship. They also support the development of relationships between FSI and the communities they serve, and are responsible for recruiting new volunteers with a particular focus on filling gaps in the network in relation to cultural diversity.

FSI has not had their services formally studied or evaluated and so are currently seeking to better understand how the program is functioning from the perspective of clients, volunteers, and staff, and how they could continue to improve and expand their program to meet the needs of the communities they serve. Furthermore, with the recent addition of the RNC role, FSI is seeking to understand how the addition of these staff members has been experienced within the program.