

Parent-to-Parent support providers: How recruits are identified

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Objective: To examine selection criteria for Parent-to-Parent support parents trained to provide support to other parents of children with disabilities.

Method: Ten leaders of Parent-to-Parent programmes participated in telephone interviews to explore attributes associated with parents selected to be trained as support parents.

Results: Qualitative analysis reveals parents deemed “ready” to become support parents, build relationships, exhibit positivity, build capacities, have good communication skills and a future orientation and feel the need to give back. An additional set of attributes we have named, “red flags” are associated with parents not suitable to provide support are also presented.

Conclusions: Parent-to-Parent support parents are informally identified by a set of characteristics that can be operationalized for screening purposes. Findings provide support for the positive influence of the peer support relationship and identify the need for a measure of parent “readiness” to assist in the recruitment of quality support parents for the Parent-to-Parent organization.

KEYWORDS

disability, early intervention, Parent to Parent, peer support

1 | INTRODUCTION

Even though the majority of parents of children with developmental disabilities adapt effectively to their caregiving roles (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003), many still experience difficult periods of time and ongoing challenges that can tax emotional and practical resources at both the individual and familial levels (Wang & Singer, 2016). Particularly in the period after diagnosis of a child's disability, parents may suffer from isolation, stress and depression due to unexpected caregiving and financial demands, perceived stigmatization and a radical disruption of their expectations about their children's future development (Singer, 2006). With time, many of these parents develop both cognitive and practical accommodations and develop perceived benefits from caring for, living with and loving their children with disabilities (Hastings, Allen, McDermott, & Still, 2002; McConnell, Savage, Sobsey, & Uditsky, 2015).

Positive parental adaptation is facilitated by formal and informal supports (Bailey, Nelson, Hebbeler, & Spiker, 2007). Informal supports are provided by lay people and can include family, friends, members of religious congregations and other parents. Formal supports are

provided by paid professionals like doctors, early intervention providers and teachers. The efficacy of formal supports has been supported in research to improve the health and academic achievement of children with disabilities and the quality of life for their families (Bailey, 2005; Feng & Sass, 2010; Kuo et al., 2012). However, formal family support services are not available in many states or regions (Braddock et al., 2015). Even when these supports are available, the complexity of the service system can be daunting. Further, some parents find that assistance from professionals is not sufficient to meet their needs for informational and emotional support (Galpin et al., 2017) and that other parents can provide a unique form of help (Bray, Carter, Sanders, Blake, & Keegan, 2017; Singer et al., 1999). Parent-to-Parent peer support programmes have become popular in the United States and other nations in response to these needs (Bray et al., 2017). Therefore, parents seek support from other informal sources.

A subgroup of informal support, peer support programmes have been shown to provide emotional and informational support for various groups of individuals such as patients with cancer, nursing mothers, those in recovery from addiction as well as parents of children with

disabilities (Boisvert, Martin, Grosek, & Clarie, 2008; Dennis, Hodnett, Gallop, & Chalmers, 2002; Hastings et al., 2002; Hoey, Ieropoli, White, & Jefford, 2008). Most peer support programmes use trained volunteers to provide support. Efficacy of such programmes has been attributed to the reciprocal nature of the relationship, the flexibility of the support and the power of shared experience, which can lend credibility to advice shared between the peers (Ainbinder et al., 1998; Santelli, Turnbull, Sergeant, Lerner, & Marquis, 1996; Shilling, Bailey, Logan, & Morris, 2015).

Parent to Parent (P2P) is an informal support programme providing parents of children with disabilities or other healthcare needs with informational and emotional support via a one-to-one match with a more experienced, trained support parent (Parent to Parent USA, 2016; Santelli, Poyadue, & Young, 2001). P2P support programmes are available in most US states and are being developed internationally (Parent to Parent USA, 2016). P2P support parent trainings take place in small groups and last 6 to 10 hrs, covering topics such as active listening, cultural diversity, sharing your story, confidentiality and local resources (Parent to Parent USA, 2010). A help-seeking parent is matched with a support parent along a variety of child- and family-specific characteristics such as child age, disability, specific systems navigation challenges, culture, language, geographic area and socio-economic or marital status (Santelli et al., 1996). The criteria used to make a match are determined by a coordinator based on an informal evaluation of the needs and concerns of the help-seeking parent. First contact is generally made by the support parent, the trained volunteer within 48 hrs. Matched dyads communicate mostly by telephone, and bonding between the parents is often attributed to the similarities in their experiences of raising a child with a disability (Ainbinder et al., 1998). It is recommended that support parents and help-seeking parents have at least four contacts over the course of 2 months (Parent to Parent, 2010).

The success and sustainability of P2P are based on the quality of these parental matches which in turn are dependent on the skills and capabilities of trained volunteer support parents. Some experienced parents who have benefited previously from a match with a support parent go on to volunteer to be trained as support parents; however, not all volunteers are accepted by P2P coordinators to serve in this role. Coordinators have to make informed judgements about whether or not a parent who expresses interest in volunteering is a good candidate. Little is known about how these parents are identified and which of their characteristics they are expected to have which are associated with their fitness to serve as help givers.

The question of who is ready to serve as a support parent reflects an important yet unresolved question in the research on parents of children with disabilities. Because P2P programmes are largely volunteer operations, it is important that their limited resources are invested in training quality support parents and not wasted on recruits who are not ready to support help-seeking parents. It is therefore imperative to create an explicit list of desirable attributes so quality support parent volunteers may be more readily identified. The purpose of this study was to ascertain which characteristics indicate to coordinators that a parent is a good candidate to become a trained support provider.

2 | METHODS

Given the absence of research examining the processes at work in preparing to support a peer in need in this specific population of parents of children with disabilities, as well as the need for comprehensive, descriptive data, an abductive qualitative design was incorporated in this study. Grounded theory (Glaser & Strauss, 1967) is a qualitative research method that begins with data collection and culminates in the development of theory grounded in the data. A modified form of it was developed by Charmaz (2006) whose methodology does not limit grounded theory to ethnographies requiring extensive and repeated observations. Modified grounded theory and related approaches are often used in research studies for which no a priori hypotheses are posited (Charmaz, 2006; Patton, 2002).

2.1 | Participants

The first two interviewees were chosen on the recommendation of an experienced researcher familiar with the organization. "Snowballing" techniques (Taylor & Bogdan, 1984) were implemented as the original participants made further recommendations for future participants and directed the researcher to the Parent-to-Parent organization's national website, p2pusa.org, with links to contact statewide member representatives. This purposive sampling strategy is commonly utilized in qualitative interview research, and Glaser (1978) suggests that researchers in the initial stages of a study "go to the groups which they believe will maximize the possibilities of obtaining data and leads for more data on their question" (p. 45). Of fourteen potential interviewees contacted, ten participated in this study (71%). They were selected based on criteria set by the researchers that they had experience in recruiting and training support parents in state, regional or local Parent-to-Parent programmes and had acted as a support parent at one time. The average length of experience in Parent-to-Parent leadership for the sample was 17.3 years with a range of four to 26 years. All participants were female and considered contact persons or leaders of the Parent-to-Parent network in their geographic area. Nine of the ten participants were biological or adoptive parents of at least one disabled child. One participant was the aunt and primary advocate for three nephews with special needs. The participants, having been help-seeking parents, support parents and coordinators in P2P at different points along their journey affords them the ability to comment from multiple perspectives. Prior to data collection, the research plan was approved by the University's Institutional Review Board.

2.2 | Interview protocol

A semi-structured interview guide was developed to provide a general structure for the researcher and to ensure that subtopic areas were addressed. Flexibility to follow the participant's lead was incorporated to allow for discovery. This interview approach is recommended when little is known about a topic as a researcher can delve deeply into the subject by adding direct probes to open-ended questioning (Harrell & Bradley, 2009). A search of major databases (ERIC, Google Scholar, PsycINFO and

PubMed) revealed no direct research exploring the question of readiness to volunteer among parents of children with disabilities.

Interviews were structured in a fashion that can be visualized in a funnel shape, beginning with large open-ended questions regarding the personal journey of participants as caretakers of children with disabilities and their experience with the Parent-to-Parent organization, followed by increasingly focused probes related to their experience with the recruitment, training and matching of parent support volunteers (Hammersley & Atkinson, 1983). Perhaps most crucially, probes of how they determined which volunteers were ready to support others, and requests for descriptions of actual and/or idealized support parent volunteers were elicited as needed. The protocol was reviewed and edited by the primary investigator in conjunction with an experienced researcher (the second author), as initial coding revealed additional topics of concern or interest.

2.3 | Data collection

Letters of introduction that included an overview of the research project, and letters of consent along with self-addressed stamped envelopes were sent via traditional post to each participant. Mutually agreeable times were scheduled for interviews via email correspondence. All participants returned signed consent letters by post. Interviewees were not provided with a copy of the interview schedule prior to the interview unless specifically requested, but were briefed by email or telephone regarding the basic areas of interest and type of information to be targeted in the investigation. Interviews were conducted by telephone or Skype to facilitate the inclusion of participants from many different geographic areas within the United States, and lasted 30 to 90 min.

2.4 | Data analysis

2.4.1 | Coding

The recorded interviews were transcribed verbatim, and line-by-line initial coding was recorded in the left-hand margin of the transcripts. Initial “open codes” were kept close to the data and made use of

gerunds to express actions in the data to keep from premature categorizing. Table 1 presents an example of the initial level of coding.

This first level of abstraction is completed to find out more about the problem and how it is being resolved (Charmaz, 2006). All names were removed to ensure anonymity of participants as well as any persons and places mentioned during the course of the interviews. A second level of focused coding involved identifying the most frequent and significant codes from the initial coding and comparing them to each other to allow for rapid movement through large amounts of data (Charmaz, 2006). Initial codes are absorbed into the more common and/or meaningful codes and all data are recoded at this level. Focused coding begins to reveal and clarify themes in the data by encouraging the researcher to note patterns of agreement and where data diverge from these themes (Table 2). The passage above is shown again below, this time with focused codes:

From this second level, a third level of overarching thematic categories was developed by sorting focused codes into categorical piles and keeping notes during this process on emerging theory related to themes. These categories were then utilized in the final coding of all interviews (Charmaz, 2006).

3 | RESULTS

3.1 | Category reduction

Following grounded theory analysis, themes identified in the interviews were reduced and grouped into five master categories: traits and concerns of P2P leaders, traditions of P2P, red flags, signs of readiness and 21st-century challenges. The two categories, signs of readiness and red flags will be discussed and illustrated with verbatim extracts from the interviews in the Results section. An analysis of the 10 interview transcripts identified a collection of attributes and their outward signs belonging to “ready” volunteers who become excellent support parents to other parents in need, as well as signs that raise suspicion that a volunteer may need further support before being trained to support others, or may never be quite ready. The subcategories within these groups may illuminate subtle processes involved

TABLE 1 First level coding of a transcript excerpt

Coded Notes	Transcription
Preparing for training of 20 volunteers. Having core values. Ability to collaborate. Learning recruit's history. Working w/stakeholders.	I think, we're getting ready to do a training on Friday and Saturday for a whole new group of, a group of 20 volunteers that are coming through this weekend to be trained, and we are, some of the questions, well we have Core Values. So, one of our Core Values is, you need to be collaborative, so we want to know a little bit about your history through the application process of how you have worked with doctors or schools.

TABLE 2 Focused coding of the same transcript excerpt

Coded Notes	Transcription
Training Support Parents Organizational Values	I think, we're getting ready to do a training on Friday and Saturday for a whole new group of, a group of 20 volunteers that are coming through this weekend to be trained, and we are, some of the questions, well we have Core Values. So, one of our Core Values is, you need to be collaborative, so we want to know a little bit about your history through the application process of how you have worked with doctors or schools.

in moving parents from being in need of support from others to being available to be the ones who provide the support.

3.1.1 | Category 1

Signs of readiness

Participants described the ways they had received support from other parents when their children were young and how they developed into leaders in Parent-to-Parent programmes. In addition to their personal experiences with peer support, participants gave examples of parents they had selected to be trained as support parents for the Parent-to-Parent programme in their region. In many of these cases, the supporting parents deemed appropriate to be trained had first come to P2P as help-seeking parents.

When participants who recruited and trained new parent support providers talked about parents who were ready to help others, they usually told a kind of idealized developmental story describing the positive steps these likely candidates had already taken prior to being recruited and trained. The ten participants characterized good candidates for parent volunteer supporters by explaining the kinds of prior experiences these parents often have had before contacting the P2P programme with an offer to volunteer. The participants also described trait-like characteristics of parents whom they perceived as good candidates to become volunteers to provide support. These included the following: building relationships through Parent to Parent, positivity, building capacities, communication skills/listening, having a future orientation and feeling the need to give back.

Building relationships through Parent to Parent

Learning from someone who is in a similar situation not only serves to normalize the experience of raising a child with special needs, but reduces the sense of isolation that many parents of children with disabilities feel, as participant 1 said, "They're not feeling so alone, they're feeling more confident." This affords parents access to opportunities to bond over similar circumstances and learn from each other.

In the following passage, a participant recalls the first time she attended a national Parent-to-Parent conference and met families whose children had the same rare genetic condition as her daughter:

It was really great to be able to talk to those parents and then learn how their daughters were able to function with the Muscle Fiber Disproportion and what that all meant and so...It's still [just] like you learn how to take stains out of things from other women doing wash at the Laundromat.

(participant 2)

The sense of belonging in being with others who understand and have moved through a set of shared experiences is evidenced by the participant's laundry analogy. This comparison of a seemingly complex exchange of information to a practical everyday task is common to Parent-to-Parent veterans, and is an example of how the language of peer support distinguishes itself from more technical professional discourse.

Accordingly, part of the answer to who should be recruited to be trained as support parents is that those parents who had received effective peer support as a help-seeking parent were more likely to go on to be ready. According to a Parent-to-Parent coordinator in the south (participant 6), "There's a real connection that happens that never happens anywhere else." The foundation upon which these peer support programmes are built is the cultivation of relationships, or "creating a sense of belonging." The participants described how for many help-seeking parents, contact with a support parent initiates a process of adaptation. Once a parent feels they have made a connection with someone who understands their feelings and experiences as a parent of a child with a disability, a bond is developed, feelings of isolation begin to dissipate, and new learning can begin.

Parents who have experienced Parent-to-Parent support are not the only people who become support parents, but many do go on to volunteer to support others in order to "pay it forward." This is evidenced by the following quote from a P2P director and board member;

But, we see a big group of parents who feel that is naturally the next step. That they are, they either got support from us, and from what we did or from some other parent program and that support enabled them to have a little bit of an easier journey. And so now they want to give back to help another parent ease their journey.

(participant 4)

This notion of a cyclical nature to peer support programmes that parents who were well supported become the next generation of support parents was expressed by several participants and will be explored further in the discussion section.

Positivity

Many participants expressed that an important attribute for potential support parents to have is a positive appraisal of their life. They explained that they were able to listen for positivity when a parent talked about her special needs child. A common early step in the recruitment process involves asking a prospective support parent to share about their experience as a parent of a child with a disability. This may be done over the telephone with a coordinator or online through a volunteer intake form. According to participants, usually they provide a coherent narrative and their attitudes are often revealed through the affective tone of their stories:

[T]hey can articulate what those dreams are, that they can if we say to them, 'share with us a description of your child' that they can share some of those real gifts and talents, that their child loves this, that their child is great at this.

(participant 4)

This positive outlook shows that a volunteer is likely to pass those emotions to a parent who is struggling and help them to improve their outlook in the process of providing support.

Building capacities

The participants in this study described a process by which parents who had received support had learned and developed new skills that they were now able to share. Potential volunteers who had gone through these enrichment and educational experiences were seen as having valuable attributes for volunteering and as a sign of readiness of a recruit to support another parent. The term “building capacities” was chosen to encapsulate activities whereby parents of special needs children had gone about learning more about their children’s disabilities, and had acquired skills or techniques to assist themselves and/or their children in daily routines. Attending conferences, conducting research on the Internet, experience navigating school and government systems and being trained in a specific intervention such as applied behavioural analysis were cited by participants as ways in which potential volunteers had built a skill set that was seen as being both beneficial in their own household and potentially valuable to others within the disability community. Participants observed that when parents first went about building capacities, their attempts often seemed to be a process of trial and error. In the following quote, a coordinator described the importance she placed on a parent’s prior self-education when the coordinator was thinking about recruiting a parent helper:

[T]hey have to have had some experience, it doesn’t have to be successful with every experience, but they have to be able to say to us which systems they have tried to navigate with their child, and that they understand the basics.

(participant 4)

In this quote, “the basics” referred to the idea that good volunteers were people who had already had some success in dealing effectively with at least some parts of the complex service systems that can be bewildering for newer parents. As these parents began to find what worked for them, their efforts were said to have become more streamlined, and focused as shown in the following quote by a former coordinator speaking in the voice of a hypothetical parent volunteer:

Maybe I’m getting a little bit gutsier with asking systems for what I need and I let them know about maybe the inaccessible playground that’s over here and, maybe I say, ‘Hey why don’t we work together on the ICC?’

(participant 1)

Potential volunteers were seen as especially promising if they were able to demonstrate that they had acquired a wide range of skills in meeting their children’s needs for support. According to several participants, there was a subset of parents who had developed a diverse set of skills. These parents held promise potentially as “universal matches” in that they were seen as potentially capable of providing support to many different parents with a range of different needs.

Communication skills/listening

Parent-to-Parent support parents were generally trained over a two- or three-day period in face-to-face training sessions with

Parent-to-Parent coordinators. The participants explained that they watched potential volunteers carefully during the training sessions in order to make a final decision about their readiness to serve as help givers in the programme. During this training, volunteers were invited, formally or informally, to share their journeys as parents of children with a disability or other health impairment. In these narratives of their life with their children with disabilities, potential recruits often discussed the pain of diagnosis, day-to-day struggles and what they were doing to make their family life work. Parent-to-Parent coordinators paid close attention to how these stories were framed as an indication of parents’ overall readiness to provide support. As most support is provided over the telephone, oral communication skills were very important attributes for a support parent. When parents could share their story in a way that could be therapeutic to others, those narratives commonly shared certain qualities that served as indicators of readiness.

Learning to tell your story is the key ingredient. That’s the most important lesson you can learn in a support parent training is knowing how to tell your story in the way that’s most helpful to the person you’re supporting. You see that a parent would tell their story, briefly, succinctly... A beginning, a middle and an end... “Well, this is my experience. This is how I am...and things that I want to be able to share are these 3 things.” Her story has been told in the comfort of her family, amongst her friends. She’s ready to share the learning points.

(participant 3)

Participants believed that parents who told effective narratives had gone through a process of developing and telling their stories well before coming to a training session. A parent who was perceived as probably not yet ready to support another parent could also be identified by markers in the way they shared their stories. Some contraindications were that they made a majority of statements that focused on themselves when sharing their story, or the story was terribly difficult or emotional for them to tell, causing the volunteer to eventually apologize or to include too many painful details. One Parent-to-Parent coordinator (participant 6) stated that the use of too many “I” statements when sharing may indicate a lack of readiness, because, “[it] doesn’t help them say what they’ve learned from this experience and how might this be helpful to another person.” Additionally, the inclusion of too many unnecessary details could indicate that a parent had not reached a point where they were able to reflect on their journey with some sense of distance from its urgency. The process of sharing their stories sometimes leads to a self-selection process. If parents could not get through the sharing of their stories because it was too difficult or brought up too much anger or sadness, they often did not return for the next day of training:

Friday night was where we told our stories and there were people who didn’t come back. And we would contact them and they wouldn’t call us back, and I think they were just

overwhelmed with everything and decided this wasn't really what they wanted.

(participant 7)

Participants believed it was important for parents be able to tell their stories without getting caught up in emotional pain or losing a focus on communicating effectively with their listeners.

Potential volunteers were also perceived to be promising as helpers if they were able to demonstrate good listening skills. Parent-to-Parent support parents were perceived as needing to be "champion listeners" which according to one participant, entailed "allowing our minds to be quiet...understanding that we're always going to have thoughts going through our brains [but] setting them aside to really listen (participant 6)." These skills were emphasized in many Parent-to-Parent trainings through role-play or video examples. Parents who could not grasp basic communication concepts were deemed unready to serve as one-to-one support providers, and subsequently were re-trained at a later date or given alternative volunteer positions within the organization. Parent supporters are expected to be able to:

Shar[e] experiences with another family and to do that in a manner that's not offending to that other family, and that they're really listening to them, not just telling them what to do but providing that emotional support and listening to them.

(participant 10)

Participants viewed listening as a key way in which volunteers would potentially help others.

[L]isten to hear what someone else is saying because that validation piece is so important. That's the piece where you know you really help that person move towards psychological health when you can understand and validate where they're at.

(participant 6)

Validating what a help-seeking parent shared could be accomplished by rephrasing their key concerns, and relating relevant stories from the support parent's own experience. During training role-plays, participants observed whether or not potential volunteers were too directive in giving advice. Successful strategies could be shared, but advice giving in the form of directly "telling someone what to do" was contraindicated for readiness as the freedom for each family to choose whichever methodology, medication or preschool they wished was a principal value of the organization. Potential volunteers who appeared to be too directive and to place advice giving over listening were reportedly not selected as volunteers.

Future orientation

In addition to a positive outlook, parents who were ready to support other parents were perceived by the informants as exhibiting a future orientation. These parents could appreciate their children for who they were in the present, and they had developed a long-term vision

with or for them. A participant defined what she meant by the term "acceptance" of the child as a requirement for a parent volunteer, "[A]cceptance means that they have dreams for their child, that they can articulate what those dreams are (participant 4)." They were able to discuss life goals for their children and family, and had thought about the intermediary steps needed to achieve them. An interviewee described an ideal "ready" parent volunteer as one who had adapted to her life as a parent of a disabled child and saw a bright future for her child and her family:

[They] have a great deal of hope, because they do. [This] is somebody who says, 'Alright, this is the hand we've been dealt, this is what we have to live with and this is what we do next.'

(participant 5)

This combination of acceptance of the children in their present conditions along with hope for them in the future was seen as an indicator of readiness. Often these future visions included steps towards independence, which were carefully measured and individualized for their children's specific needs. A coordinator used her own experience to illustrate this future orientation. In trying to explain the kind of hopeful outlook she thought was an important indicator of readiness to volunteer, she talked about her own experiences as a prototype:

[W]e were really pushing her education teams since she was about 8-years-old, 9-years-old that she would not be probably someone who would be working in a typical job. In an office or a store, or something that maybe I would do, and so we needed to be really creative and customize a job for [her], and most likely start her own business.

(participant 4)

This type of insight into their children's needs and interests is necessary for long-term planning, and may be noted more frequently in parents of older children who have had more time to adapt their goals.

Feeling the need to give back

Once a parent had experienced multiple successes with their child or within their family and developed a sense of empowerment, participants indicated that many parents felt an urge to give back to the disability community. Some seasoned parents felt that it was a responsibility to "pay back" the support they were given. One Parent-to-Parent coordinator shared her own desire earlier to volunteer for Parent to Parent, saying that she had wanted "to be a support to other parents because [she] got some good support when [her] children were born." Another motivation cited by participants that parent volunteers shared was to "pay it forward (participant 8)", that is, to save others from some of the difficulties they had experienced along their journey:

They want to help another parent, maybe not go through what they did if their experience had not been great... they

had some experiences they really want to make sure don't happen to other families.

(participant 4)

According to the participants, parents could also feel they needed to give back to other parents who may be in a similar place that they had been in previously in order to impart a sense of hope. They could share how they had progressed through difficult times such as health crises and self-injurious behaviours to find a sense of humour and strength in their role as a parent of a special needs child. When parents began to talk about wanting to give back, it may mark a realization on their part that they have acquired skills, contacts and understandings that not only help their immediate family, but may benefit others. As a participant 5 shared:

That they've survived a lot more than they've realized, and that they've come out of it...Come through...to know that they do have something to share...I could teach somebody something!

(participant 5)

This transformation from being the parent in need of support to the parent ready to provide support required the parent to find meaning in their journey, and imbued them with a newfound confidence and resilience.

3.1.2 | Category 2

Red flags

Coordinators were responsible for identifying individuals who could become an effective support parent and those who might not yet be ready. They reported certain warning signs in listening and observing a parent attending a training session and who had expressed an interest in becoming a support parent. The coordinators usually were able to observe applicants during workshops designed to train newly recruited helpers. In the course of these meetings, the coordinators had the opportunity to observe how candidates talked about their experiences as a parent of a child with special needs.

Interestingly, many participants independently offered paradoxical examples describing behaviours and personality traits of an individual who would not be ready to take on the role of support parent in response to the main question of, "How do you know a volunteer is ready?" Participants found it easier to pinpoint such "red flags" when asked to describe what a parent who was "ready" would say or do. As this trend became apparent during early data analysis, the interview protocol was altered to elicit additional information on this topic. The subcategories included in this theme are as follows: negativity, being stuck, being judgemental and looking for cures.

Negativity

Communicating negativity was a common "red flag" related by participants. Some parents were described as expressing a negative appraisal of their current situation. One coordinator (participant 6)

talked about a parent who clearly was not ready to become a support provider: "[She was] negative and her world was a disaster and everybody hated her." Examples of parent negativity could also involve the way in which a parent spoke about stakeholders in their child's health or education. Although discussions regarding dissatisfaction with services for their children and specific service providers were common in a Parent-to-Parent match situation, one coordinator (participant 4) described consistent negative attributions about professionals as a sign of unreadiness: "Do they complain about the doctors on the interview with us? Do they complain about teachers?" This inability to control the urge to express discontent with service providers could be problematic if shared with a help-seeking parent. Some of the participants attributed negativity to an individual's personality and saw it as a fixed trait. A participant expressed her view that not all parents of children with disabilities will come to see the experience of parenting as positive, just as parents of "typically developing" children may not necessarily find joy in their child-rearing experiences.

People who tend toward being depressed or toward being angry can have a child with a disability, and sometimes it just gives them a fine damn reason for them to be that way.

(participant 2)

Delivered in a matter-of-fact tone, this participant seemed to project an acceptance of parents who may be perpetually angry and never appropriate for the job of support parent. Other interviewees indicated that additional training or support could assist a parent in moving past such negativity. Negativity was also thought to be related to the constantly changing needs of having a very young child with a disability or health needs, as evidenced by participants from a few Parent-to-Parent member networks sharing their recruitment guidelines of not training parent volunteers with children under three years old or inside of a six-month window since diagnosis.

Being "stuck"

Parents who routinely expressed negativity in sharing their story were often seen as being stuck in this place, unable to move beyond their current unhappiness. An interviewee talked about the state many parents of children with disabilities or special healthcare needs were in when they first reached out to a regional centre or other local organization for assistance:

[They have] so much of a lack of knowledge of a certain area that they don't know quite how to move forward.

(participant 1)

This inability to progress was often associated with the "pain of diagnosis." Participants mentioned that this initial pain was one that persists through the lifetime of a parent, but is usually counterbalanced by feelings of pride and positive adaptation which occur as a parent learns more about their child and adjusts their expectations for their child and

family accordingly. However, a parent who is stuck will “rehash the same stuff” every time she speaks with another parent in a way that indicates that she is “angry and not in a good place.” Parents who are stuck may not be able yet to be matched with a support parent as being “stuck there, prevents you from being somebody who can have a relationship.” These parents were often referred to mental health services for counselling in order to “find some place to be okay with what’s happening (participant 6).” It was recognized that these parents often changed for the better over time with the right kind of assistance. However, until they became “unstuck,” they were viewed as not yet ready to serve as volunteers.

Being judgemental

When parents remained entrenched in negativity and entered the “stuck” state, several attributes or actions were noted as “red flags.” Being judgemental can be readily identified through careful listening during conversation. Parents who tell others what they have to do rather than phrasing their sharing as what worked best for their family or child may be judgemental and make others feel they have limited choice and power in their lives. This attitude was perceived as harmful to help-seeking families, who were described as looking to discover the array of options available for them along their journey with their child. Coordinators listened carefully for “loaded, value-laden words” and negative, inflexible positions regarding specific stakeholders or methodologies, as was expressed by a veteran Parent-to-Parent coordinator (participant 4):

[S]tatements that we’re going to cringe when someone says, ‘I really hate Doctor Taylor,’ or, ‘I would never refer a parent to Doctor Taylor,’ or, ‘I believe only in cochlear implants,’ or, ‘Only in ABA.’

Looking for cures

The pain of receiving a diagnosis for their child was often mentioned as a hurt that will never go away, but the shared belief of participants was that fixation on it is something to move past. Some parents though were described as unable to come to terms with their child’s disability and will put a great deal of energy into finding a cure. These parents may find themselves stuck in the pain of the diagnosis and cannot move forward in their journey with their disabled child, let alone assist anyone else in theirs. The families of these parents were seen as constantly in flux, rushing to multiple doctors, homeopaths, therapists and nutritionists (to name but a few), and altering family routines repeatedly to accommodate the latest treatment promised to eliminate all symptoms of their child’s disability. This repeated and unrelenting searching behaviour was seen as inhibiting the process of a family’s adaptation to the child’s disability, and as decreasing the time the family spent together as a unit. Participants strongly cautioned against using parents who were actively looking to cure their child as support parents.

Some diagnoses have received more attention in the realm of cures, and parents may put a great deal of money and energy into

special diets, therapies or holistic or experimental medical procedures in hopes of having a “normal” child. Participants often cited autism as being a particularly difficult diagnosis to accept:

And, unfortunately, autism is the one that’s got the most options out there. Of people saying, ‘Do this and your child will be cured of autism.’

(participant 7)

If a parent was perceived as not yet able to accept the permanence of their children’s disabilities, and appreciate them for the positive things they already brought to their families, they were not ready to move forward in their journey and create goals and plans for the future. This did not mean that good volunteers were not finding helpful training and supports for their children or providing them as parents, but it meant that they were not over-focused on interventions that they thought would result in total cures.

Looking to cure a child was perceived as indicative of a parent who sees their child’s disability as wholly negative or is in a state of panic. The parent was seen as not ready to become a support parent, but could benefit from some kind of peer-support herself. This could be in the form of a coordinated support group or a one-to-one match with a more experienced parent who had come to accept their child with autism for exactly who they were. Hearing from a parent who had arrived at a stance of hopeful acceptance could impart hope, acceptance of the diagnosis and decreased stress associated with repeatedly adopting rigorous curative protocols.

Participants stressed the importance of connecting all potential supporting parent recruits deemed “not ready” with appropriate services and supports. Rejected volunteers could be offered a Parent-to-Parent match, referred to mental health services or placed in alternative volunteer positions. An example of how P2P coordinators may choose to navigate this type of scenario was shared by participant 6 and is presented below.

[W]hen you find (a support parent volunteer) that may not be the best fit you hope to get them connected in a way that their fit will be better. And there was one parent who just didn’t get it, as hard as I tried during the training to help her to get the reflection and open ended questions and the relationship piece of it beyond her own and I think that she was still grieving. So, she wasn’t quite ready but one of the things she identified was that she just loved to hold babies so I thought well what better place for her then to connect her to an NICU with a program for people to come in and hold babies.

The individualization of the role provided to the parent described above, along with the focus on providing the parent with the support she needed to begin to adapt to her child’s disability, is a manifestation of P2P’s belief in the strength and resiliency of parents and commitment to supporting families.

4 | DISCUSSION

A parent who has a positive outlook while balancing the complicated situation of caring and advocating for a child with a disability or chronic health condition can be an especially powerful and transformative model for the people to whom they provide support (Trute, Benzies, Worthington, Reddon, & Moore, 2010). It is therefore important to choose high-quality support parents to provide information and emotional support to help-seeking parents who request a Parent-to-Parent match. The categories identified in this study revealed the perceptions of a group of leaders of Parent-to-Parent peer support programmes from several states in the United States. When asked how they determined whether to recruit a parent as a volunteer helper, they identified traits and behaviours of parents deemed “ready” to be trained to provide support to other parents of children with disabilities as well as “red flags” that indicated a parent should not be utilized in this capacity yet. These traits can be used to help identify suitable support parent volunteers especially in new P2P organizations or when the volunteer is not well known by the coordinator. A checklist of these traits along with examples could be helpful for coordinators to have available for reference during support parent trainings when volunteers often reveal their disposition and life appraisal during conversations about their journey as a parent of a child with a disability. By operationalizing these positive and negative signs of readiness, P2P coordinators can be more confident in their decisions regarding the selection of quality recruits to match with help-seeking parents and the rejection of volunteers who display too many “red flags” and may require further training or support.

4.1 | Limitations and future directions

A limitation of this study was the homogeneity of the subjects. The majority of the interview participants were Caucasian, middle-class, middle-aged women. A parent’s reaction to their child’s disability may be different in samples of women from culturally and linguistically diverse groups, younger parents, parents of low socio-economic status, LGBTQ families and fathers and needs to be examined more fully. Additionally, the efficacy and acceptability of a one-to-one support paradigm require further exploration through study of these populations.

Future research utilizing the categories in this study to develop a measure of readiness to be a support parent for Parent to Parent is needed. A measure can help coordinators more efficiently screen potential volunteers over the telephone or by an Internet link made available on their website. This is important when little is known about the volunteer to ensure they are ready to provide support to another parent before inviting them for training. Support parent trainings are among the largest costs of starting or maintaining a P2P programme and funds must be allocated wisely. If a volunteer were to score well on a measure of readiness, a coordinator could feel more confident they made a smart investment.

High-quality recruits chosen to be trained after being screened with this measure may then impart their positivity to help-seeking families, restarting the peer support cycle suggested by the participants in this study, where help-seeking parents who receive good support from a support parent go on to volunteer as support parents. This measure may also be applicable more directly as an assessment of a parent’s adaptation to their child’s disability and could be utilized by other disability-related volunteer organizations, for programme evaluation or in research studies designed to impact parental coping. Research could then determine whether such a measure might have construct validity when utilized in other peer support organizations serving different populations. It may be that there are commonalities in the way people who undergo difficult life challenges adapt and share what they have learned by helping others.

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