

**RESEARCH ARTICLE**

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# Meeting families where they are: Text-based support in parent to parent programs

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**Abstract**

**Background:** Social support can be an important buffer to stress to parents when their child has a disability. Parent to parent (P2P) is an evidence-based peer support program for parents of children with disabilities, where support is provided over the telephone. However, younger parents may prefer electronic communication platforms.

**Methods:** This paper reports on the results of an online survey of P2P stakeholders regarding: How text-based support is being used in P2P programs and whether text-based support is perceived as providing benefits to parents of children with disabilities. A 13-item survey was developed, which included 10 opportunities to provide Likert, nominal, ordinal and dichotomous responses, as well as three open-ended questions. Thirty-one P2P coordinators participated.

**Results:** The majority of participants reported that text-based support was provided regularly in support relationships, most frequently to parents between 25 and 34. The most common platforms used included email and text messages, private Facebook groups and the Facebook Messenger application. Participants indicated that most P2P programs did not have a written policy or guidelines regarding text-based support. Qualitative themes of best practice, connection, (mis)understanding, convenience, preferences and privacy are also presented.

**Conclusion:** Because parents of young children are frequently referred to P2P programs for information and support, it is important the P2P program adapts to the preferences of a new generation while continuing to provide reliable and effective support. (word count: 225).

**KEYWORDS**

parents of children with disabilities, peer support, social media, text messaging

## 1 | BACKGROUND

Social support can be an important buffer to stress to parents when their child has a disability. They may have unanswered questions, unexpected emotional responses and difficulty knowing what they should do to help their child develop (Dodds, 2015). Parents of children with disabilities or special healthcare needs require different types of support which may include: (a) *informational support* to find

reliable information related to their child's disability, (b) *navigational support* to learn how to secure proper supports and services for their family and (c) *emotional support* to assist them in adapting and coping with their child's disability (Dodds, Yarbrough, & Quick, 2018). Communication with professionals, however, can be inadequate in addressing these needs, and further may be perceived as insensitive to the input of the family (Wodehouse & McGill, 2009). Parents of children with disabilities often require more personal information

(Quine & Rutter, 1994) and services that are responsive to their specific needs and provide practical guidance for parenting their child (Division of Early Childhood, 2014). Family-centred practices like peer support are associated with long-term reductions in parenting stress (Guralnick, Hammond, Neville, & Connor, 2008) and improvements in parenting self-efficacy, parent well-being and child behaviour (Dunst, Trivette, & Hamby, 2007).

Parents of children with disabilities are frequent consumers of online information related to their child's condition and access social media and internet forums to meet their need for social support from other parents (Nicholl, Tracey, Begley, King, & Lynch, 2017). Online social support can reduce barriers related to geography and time for parents of children with disabilities, making others with similar experiences all over the world instantly accessible (Park, Kim, & Steinhoff, 2016). Building a social support network in this way may decrease the isolation parents' experience, especially when their child has a rare condition (Baumbusch, Mayer, & Sloan-Yip, 2018). Further, the need for parents to make online connections may be particularly salient during health crises like the current COVID-19 pandemic. While peer support provided over the internet is generally well received and no harmful effects have been reported thus far, current evidence for the effectiveness of online support for parents of children with disabilities is inconclusive (Niela-Vilén, Axelin, Salanterä, & Melender, 2014).

Parent to parent (P2P) is a peer support program available in 36 U.S. states and the District of Columbia that provides parents of children with disabilities with support via a one to one match with a more experienced trained support parent. The parent seeking help, the Referred parent, is matched to a support parent along a variety of child and family specific factors (Santelli, Turnbull, Sergeant, Lerner, & Marquis, 1996), creating a sense of perceived sameness, where support and information shared is seen as reliable (Ainbinder et al., 1998). The benefits of P2P support include meeting specific informational needs, as well as improved coping, a more positive orientation and personal growth (Dodds & Singer, 2017; Singer et al., 1999).

According to the *Parent to Parent USA Endorsed Practices for Parent to Parent Support*, support parents should make at least four telephone contacts within the first 2 months of the match, as satisfaction increases with the number of contacts with the Support Parent (Singer et al., 1999). P2P coordinators who are paid employees responsible for arranging the match, call the referred parent to make sure first contact has been made, check the goodness of fit between the two parents, and to answer any additional questions that the referred parent may have. The coordinator later contacts both the referred parent and the support parent after 8 weeks to evaluate the success of the match in meeting the needs of the referred parent.

Each P2P program must affirm annually in response to the *P2P Director's Survey* that they commit to follow the endorsed practices described above, in order maintain affiliation and display the P2P logo on their website and promotional materials. Respondents to the 2016 survey indicated that although nearly all followed up on matches, only 12% of programs responded that all matches completed four or more calls, and further, nearly one-third of programs are not even tracking

### Key Messages

- Parents of young children with disabilities may prefer online resources for information and support to telephone and face to face meetings with peers.
- Parent to parent peer support providers are utilizing text-based platforms to provide peer support.
- Parent to parent programs need to develop guidelines for providing text-based peer support.
- It is unknown whether online/text-based peer support provides similar benefits to telephone support for parents of children with disabilities.

these data (Parent to Parent USA, 2017). According to unpublished data from a completed interview study of P2P directors, engaging young parents in a peer match has become an increasing challenge, with one informant sharing that despite the endorsed practice rules, she is 'going to communicate with people through whatever platform works for them'. In this spirit, many P2P organizations now offer online training and webinars to parents on a variety of topics and make use of social media pages to communicate with the families they serve in their State. Because P2P USA's guidelines are based on research conducted over 20 years ago, it is important to begin to examine the way support is being provided in P2P programs so that the organization can continue to provide quality support to the parents they serve. Therefore, it is important to explore:

1. How text-based support is being used in P2P programs; and
2. Whether text-based support is perceived to provide similar benefits to telephone or in-person support for parents of children with disabilities.

## 2 | METHOD

To answer the research questions above, a 13-item survey was developed (see Appendix A), which included 10 opportunities to provide Likert, nominal, ordinal and dichotomous responses, as well as three open-ended questions with space to type a qualitative text response. We developed quantitative survey items to elicit information regarding the frequency of utilization of text-based support, popular platforms (text-message, Facebook and so on) and whether individual P2P programs provided coordinators with guidance on their use. Additional items were developed to explore the relative utility of text-based communication in providing the different types of support frequently required for parents of children with disabilities, namely, emotional (listening and validation), informational (facts and impressions) and navigational (navigating healthcare and education systems). Qualitative, open-ended items were developed to allow participants to include information, lessons-learned, evaluations and anecdotes

that were not addressed by multiple-choice items. For instance, if a participant indicated that, yes, they had concerns regarding the provision of text-based support, they were prompted to, '[T]ell me about your concerns'. All participants were then asked to elaborate on, '[w]hat else ... [the researcher] should know about text-based support' and '[w]hat else [they, the Coordinator] want to know about text-based support?' The survey took participants an average of 8.6 min to complete. The brevity of this survey may be responsible for the relatively low attrition rate described below.

Coordinators were chosen as informants for this study because they train, match and follow-up with hundreds of support parents each year and are therefore most likely to have the most accurate information regarding what is occurring within matches in their program. In 2018, P2P coordinators across the country trained nearly a thousand new support parents and made 8850 one-to-one matches (Parent to Parent USA, 2019). All study activities were approved by the University Institutional Review Board prior to data collection. The author sent email introductions to P2P directors across the United States whose email addresses were publicly available at p2pusa.org to explain the scope of the project. A recruitment flyer with a reusable survey link was attached to the email for distribution. Directors then were able to choose to forward the recruitment flyer which explained that participation was voluntary to their Coordinators. No incentives were provided.

All data were collected online using a secure University survey portal open for 1 month between May 15 and June 14, 2018. No identifying information was solicited or captured, so the researcher was unable to contact participants who logged in to remind them to complete the survey. All available data are included in this report, and due to the small sample and exploratory nature of this research, only frequencies will be reported for quantitative items in this manuscript. Qualitative responses were first summarized line-by-line in the margin, next, summaries were collapsed into codes and subsequently codes were sorted thematically (Corbin & Strauss, 1990). These themes will be summarized and verbatim examples will be presented.

### 3 | RESULTS

#### 3.1 | Quantitative

Forty-three participants began the survey, and 31 completed at least three items, which represents a 72% participation rate, superior to similar survey research focused on families and disability-serving organizations (Hill, Lightfoot, & Kimball, 2010; Parette, Meadan, Doubet, &

Hess, 2010). Participants were all female and one participant indicated bilingualism in Spanish and English. All P2P coordinators revealed that the support volunteers they supervise are using text-based platforms most frequently with parents between the ages of 25 and 34 (85%). As shown in Table 1, nearly 70% of respondents claim that some type of text-based support was provided in the majority of support relationships and that a 1:1 match was still made for parents who requested text-based support 'most of the time' or 'always' according to 69% of respondents. The most commonly reported platforms utilized for the provision of support can be seen in Figure 1, below, with email and text messaging being the most frequently named, followed by private Facebook groups and the Facebook Messenger app.

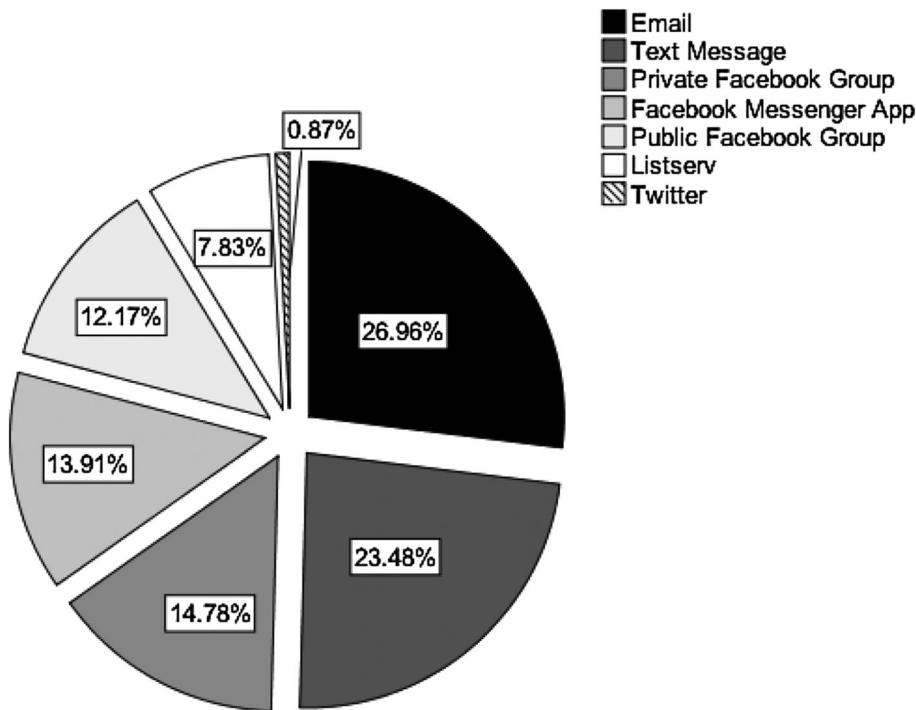
Participants responded to Likert items to compare text-based support to telephone support for three types of support typically required by parents of children with disabilities; informational, navigational and emotional support, described earlier in this paper. For informational and navigational support, the majority of respondents reported text-based support being about the same or better than telephone support, however in the case of emotional support, most respondents felt that text-based support was inferior to support provided over the telephone (see Table 2). Participants indicated that most P2P programs had neither a written policy regarding the provision of text-based support nor specific guidelines for its use.

#### 3.2 | Qualitative

Three open-ended questions were asked of study participants, the first of which, 'Tell me about your concerns', was only displayed to participants who answered 'yes' the preceding item which asked if they had any concerns about text-based peer support. The following two questions, 'What else do you want to know about text-based support?' and 'What else do you think I should know about text-based support?' were visible to all participants. Twenty-six respondents provided answers to one or more of the open-ended questions with an average of 18 responses per item. The responses to all open-ended questions were summarized line-by-line in the margin with open codes, open codes were then collapsed into more general codes and sorted thematically (Corbin & Strauss, 1990). Themes that emerged during this process regarding text-based support for parents of children with special needs, in descending order of frequency, included best practice, connection, (mis)understanding, convenience, preferences and privacy. These themes were shared with an advisory committee of five P2P stakeholders with varying positions within the organization for feedback and validation. The advisory committee

**TABLE 1** How often text support is provided and matches are made when text is requested

Text support provided ...	1–25% of the time	26–50% of the time	51–75% of the time	76–100% of the time	Total
Percent (count)	6.9% (2)	24.1% (7)	44.8% (13)	24.1% (7)	100% (29)
Match made for text request ...	Never	Sometimes	About half the time	Most of the time	Always
Percent (count)	0% (0)	17.2% (5)	13.8% (4)	41.4% (12)	27.6% (8)



**FIGURE 1** Text-based platforms used to provide support

**TABLE 2** How text-based support compares to telephone support

Type of support	Much better	Somewhat better	About the same	Somewhat worse	Much worse	Total
Informational	6.7% (2)	30% (9)	43.3% (13)	16.7% (5)	3.3% (1)	100% (30)
Navigational	6.7% (2)	26.7% (8)	40% (12)	20% (6)	6.7% (2)	100% (30)
Emotional	0% (0)	6.7% (2)	26.7% (8)	50% (15)	16.7% (5)	100% (30)

discussed their personal and professional experiences with text-based support and unanimously confirmed the author's findings.

The theme of best practice encompassed anecdotal evidence P2P coordinators shared regarding the most effective ways to use text-based platforms to provide support, including when and how it should be used. In the experience of one coordinator, 'it seems that an initial phone call then followed by text support works well', but participant 14 shared a different point of view, 'as we always say around here, it is hard to explain Medicaid via a text'. *Best Practice* also included participants' desire for more guidance from their overarching National Organization, P2P USA in the form of research comparing telephone and text support as well as a top down program policy document. Participant 27 shared that they would 'like to see fact-based comparison results of effectiveness in the near future', and participant 22 said that 'It would be great to know if there are guidelines we should be sharing with support parents'.

The theme connection regarded the bond or relationship that developed between parents who shared similar experiences with their children. Because previous research has shown that P2P support is most beneficial when a close bond is formed, the quality of the relationship between the support parent and the referred parent was seen as very important to the integrity of the peer support program. Participants often reported concern that without hearing each other's

voice, that parents may not experience the same connection. Participant 16 shared her doubt about the ability to bond over text platforms saying, 'establishing a trusting relationship with the parent is difficult when you cannot pick up on nuances in the parent's emotions, etc. that you might get while on the phone with them. It feels like there is a wall (no emotions) when you are just texting'; however participant 17 expressed encouragement that in developing a relationship by text-based communication, 'emojis help a lot!'

The theme of (mis)understanding also related to the loss of important tools for conveying empathy and information such as, tone of voice and acknowledgement (nodding) in text-based communication, as well as personal experiences of misunderstanding in text message and email correspondence. Participant 2 put this simply, writing, 'It is easy to misconstrue written text', and participant 17 elaborates her experience, '[it] is how the information is perceived. We may post something with good intentions, but it could be accepted differently than we are giving it'.

Convenience emerged as a positive aspect of text-based support for modern families. Participant 1 shared that they 'have parents ... who request email or text support because they can't find the time to connect by phone'. And participant 7 adds that 'getting support with texting is an easy way to ask questions and can be done at a convenient time for parents'. Coordinators noted that text messages also

facilitated speedier intake and matching processes and assisted support parents in scheduling telephone calls with the families they serve, so that parents seeking support received it sooner.

Preferences and privacy were less frequently elicited by open-ended items, but were preserved as themes due to their importance in discussions around modernization of the P2P program of support (Dodds, 2014) and data security concerns ubiquitous in our culture. *Preferences* included participant discussions of coordinator respect for the choices of parents who request support through text, allowing the support parent to decide if they are comfortable honouring the request. This is illustrated by a quote from participant 1, who suggested that after the initial connection by telephone, 'it is up to the parent and peer supporter to decide what method of communication works best going forward'. *Preference* was also noted in relation to specific groups such as 'younger military' parents as shared by participant 12. *Privacy* encompassed sentiments related to the fear of data 'breaches', 'hacking' and other unknown 'ramifications' of digital communication. Respondents were also concerned that parents shared very personal emotional information over social media platforms, which participant 17 cautioned 'could be accepted differently' than intended.

## 4 | DISCUSSION

Because parents of young children are frequently referred to P2P programs for information and support, it is important the program adapts to the preferences of a new generation while continuing to provide reliable and effective support. Our finding that the majority of parents supported through text-based platforms are between the ages of 25 and 34 aligns with previous research showing millennial parents are most likely to use text-based platforms to meet their information and peer support needs (Bensley et al., 2014; DeHoff, Staten, Rodgers, & Denne, 2016). Although P2P USA continues to require parents communicate by phone at least four times, according to our data, this is unlikely to be occurring in matches with younger parents who increasingly are avoiding telephone calls, preferring text-based communication through email or chat features seen as more polite and efficient (Meek, 2018). Additionally, parents of younger children may have difficulty making time in their busy schedules to talk on the phone. Therefore, technology may provide superior accessibility for family-focused support than one-to-one matching programs (DeHoff, Staten, Rodgers, & Denne, 2016).

Our quantitative and qualitative results do also highlight the importance of matching the type of support provided with the need or stressor expressed by the referred parent. For example, a response to a need for more information on a therapy or educational resource is easily conveyed by text. However, when a referred parent is experiencing negative emotions related to their child's disability, this type of need should be matched with quality emotional support (Cutrona, 1990), with telephone or face to face communication prioritized to decrease the likelihood of misunderstandings and improve the clarity of communication. Previous research comparing text-based

and face to face support revealed that the absence of tone of voice in text-based support made the interpretation of emotional affect difficult (Liess et al., 2008). This may be why researchers have suggested that online communication generally provides a support experience that is less connected, less satisfying and less effective than telephone or in-person communication (Knop et al., 2016; Lewandowski, Rosenberg, Jordan Parks, & Siegel, 2011; Sacco & Ismail, 2014). Further, emotional support provided by text may impede bonding between referred and support parents, thus reducing or possibly nullifying the benefits of P2P support.

The findings of this research have implications beyond peer support programs for educators, healthcare professionals and social workers who serve families of young children with disabilities or special healthcare needs. While many professionals who come into contact with families of young children with disabilities or special healthcare needs focus on intervention and treatment for the child, it is well known that the child's condition can pose challenges for the entire family. Negative impacts can include financial challenges, stigma and isolation and depression (Cohrs & Leslie, 2017; Saunders et al., 2015; Werner & Shulman, 2014). However, perceived social support has been shown to reduce the impact of the diagnosis on the family and foster benefit finding in parents of children with disabilities (Cantwell, Muldoon, & Gallagher, 2015; McConnell, Savage, Sobsey, & Uditsky, 2014). Therefore, prioritizing peer support and community building early on may promote greater family resilience, improving the impact of educational and healthcare efforts. In addition to connecting families to formal services, professionals should provide linkage to local programs where families can access education and training related to their child's disability as well as peer support. Social workers can also suggest vetted online informational resources from trusted organizations and moderated social media support platforms, so that parents can avoid some of the misinformation commonly dispensed on the internet and guide families to seek face-to-face or telephone support from other parents when they are in need of emotional support.

## 5 | LIMITATIONS AND FUTURE DIRECTIONS

Limitations of this study include the small sample size, brevity of the survey and choice of respondents. Because text-based support is not currently endorsed for use by P2P USA, the National Consortium of P2P programs, all responses to the survey were completely anonymous, so that the location of respondents and comprehensive demographic information were not recorded. An additional limitation of this study is that P2P coordinators were used as informants rather than support parents who do the work of providing support or the parents of children with disabilities receiving support. Because coordinators train and match hundreds of parents each year, their knowledge of the support being provided is vast, but second or third hand.

Additional quantitative research, supported by P2P USA, will be needed to gain a more nuanced understanding regarding how text-

based platforms are being used within the P2P support relationship in various geographic regions of the United States. This research will need to consider the length and frequency of text-based communications as well as the perceived efficacy of the P2P matches, as the amount of support provided in total may be more meaningful than the number of exchanges alone. Qualitative research engaging P2P programs that primarily serve young families through connections with early intervention programs should also be conducted to identify referred parent preferences and emerging best practices for the provision of text-based support. This research could be conducted in collaboration with a P2P advisory board to develop updated P2P USA support guidelines. (word count: 3285)

#### 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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## APPENDIX A.

**TABLE A1** Online survey items and corresponding response options

Online survey item	Response options
1. How often do your supporting parents/parent navigators use any text-based modalities to provide support to help-seeking parents?	1–25% of the time, 26–50% of the time, 51–75% of the time, 76–100% of the time
2. Which text-based platforms do your supporting parents/parent navigators utilize? Check all that apply.	Text messaging, private Facebook group, public Facebook group, email messages, Facebook messenger
3. When a parent requests text-based support, is a P2P ‘match’ made?	Never, sometimes, about half the time, Most of the time, always
4. Does your organization provide supporting parents/parent navigators with text-based support guidelines?	Yes, no
5. Does your organization have a written policy regarding text-based support?	Yes, no
6. Help-seeking parents who request/prefer text-based support are most frequently between the ages of:	18–24, 25–34, 35–44, 45–54, over 55
7. How do you think text-based support compares to telephone support in providing informational support?	Much better, somewhat better, about the same, somewhat worse, much worse
8. How do you think text-based support compares to telephone support in providing emotional support?	Much better, somewhat better, about the same, somewhat worse, much worse
9. How do you think text-based support compares to telephone support in providing navigational support?	Much better, somewhat better, about the same, somewhat worse, much worse
10. Do you have concerns regarding text-based support?	Yes, no
11. Tell me about your concerns.	(text box provided)
12. What else do you think I should know about text-based support?	(text box provided)
13. What else do you want to know about text-based support?	(text box provided)