

Research Article

Revised Conceptual Framework of Parent-to-Parent Support for Parents of Children Who Are Deaf or Hard of Hearing: A Modified Delphi Study

Rebecca J. Henderson,^a Andrew M. Johnson,^a and Sheila T. Moodie^{a,b}

Background: A scoping review of the literature was conducted, resulting in the development of a conceptual framework of parent-to-parent support for parents with children who are Deaf or hard of hearing. This is the 2nd stage of a dual-stage scoping review.

Purpose: This study sought stakeholder opinion and feedback with an aim to achieve consensus on the constructs, components, and design of the initial conceptual framework.

Research Design: A modified electronic Delphi study was completed with 21 handpicked experts from 7 countries who have experience in provision, research, or experience in the area of parent-to-parent support. Participants completed

an online questionnaire using an 11-point Likert scale (*strongly disagree* to *strongly agree*) and open-ended questions to answer various questions related to the descriptor terms, definitions, constructs, components, and overall design of the framework.

Results: Participant responses led to the revision of the original conceptual framework.

Conclusion: The findings from this dual-stage scoping review and electronic Delphi study provide a conceptual framework that defines the vital contribution of parents in Early Hearing Detection and Intervention programs that will be a useful addition to these programs.

Parent-to-parent support is a mutual process of parents with lived experiences supporting each other.

For parents raising children with disabilities, parent-to-parent support yields many positive benefits and rewards and leverages peer partnership so that parents are encouraged and supported in ways that are meaningful to them. Evidence of the benefits of parent-to-parent support is recognized in the literature for children with autism spectrum disorder, birth defects, chronic disease, cognitive disabilities, cystic fibrosis, developmental disabilities, limb deformities, and mental health disorders (Banach & Couse, 2012; Barlow & Ellard, 2006; Baum, 2004; Hoagwood et al., 2010; Ireys, Chernoff, Stein, DeVet, & Silver, 2001; Kerr & McIntosh, 2000; Law, King, Stewart, & King, 2001;

Mathiesen, Frost, Dent, & Feldkamp, 2012; Olin et al., 2014; Resch et al., 2010). Parents recognize that interacting and colearning with parents in similar situations contributes to parental and family well-being.

For parents of children who are Deaf or hard of hearing (D/HH), parent-to-parent support has an important role in helping parents provide assistance to their children (Åsberg, Vogel, & Bowers, 2007; Bradham, Houston, Guignard, & Hoffman, 2011; Brown & Remine, 2008; Dalzell, Nelson, Haigh, Williams, & Monti, 2007; Eleweke, Gilbert, & Bays, 2008; Fitzpatrick, 2010; Fitzpatrick, Graham, Durieux-Smith, Angus, & Coyle, 2007; Hardonk et al., 2013; Jackson, 2011; Jackson, Wegner, & Turnbull, 2010; Jamieson, Zaidman-Zait, & Poon, 2011; Larsen, Muñoz, DesGeorges, Nelson, & Kennedy, 2012; Lederberg & Golbach, 2002; Muñoz, Blaiser, & Barwick, 2013; Poon & Zaidman-Zait, 2014; Sipal & Sayin, 2012). When a child is diagnosed with a hearing loss, the majority of these children are born to parents with typical hearing who were not expecting the diagnosis (Bagatto, Scollie, Hyde, & Seewald, 2010; Mitchell & Karchmer, 2004). Peer parents can provide empathetic support, knowledge, and skills to facilitate the navigation of this new experience.

^aHealth & Rehabilitation Sciences Program, Faculty of Health Sciences, University of Western Ontario, London, Ontario, Canada

^bNational Centre for Audiology, Faculty of Health Sciences, University of Western Ontario, London, Ontario, Canada

Correspondence to Sheila T. Moodie: sheila@nca.uwo.ca

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This support system may be referred to as *family-to-family support*, *peer-to-peer support*, *peer-mentor support*, *parent coach or guide*, or *one-on-one parent support*, but the term *parent-to-parent* best characterizes the system of support described by parental narratives in the peer-reviewed literature. For parents of children who are D/HH in this study, the word *parent* is used broadly to refer not just to parents but to primary guardians and caregivers.

It is imperative that audiologists who wish to deliver child- and family-centered care (C&FCC) recognize, value, and champion parent-to-parent support. Well-informed audiologists focus on family needs inside and outside the clinic. They provide parents with diverse opportunities to share their experiences and develop additional knowledge. Parent-to-parent support empowers parents to be collaborators in clinical practice (Luterman, 2015).

An international consensus document titled “Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing” (Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013) provides 10 guiding principles to family-centered care intervention. Principle 4 identifies family social and emotional support as a priority, stating that “families are connected to support systems so they can accrue the necessary knowledge and experiences that can enable them to function effectively on behalf of their D/HH children” (Moeller et al., 2013, p. 435). Providers and organizational decision makers are given objectives to achieve Principle 4 and are encouraged to

ensure that all families have access to parent-to-parent support from other families of children who are D/HH. Recognize the key role of parent-to-parent support in promoting social and emotional well-being for families. Recognize and actively support parent organizations and networks for direct parent–peer support opportunities. Support connections between families and adult role models who are D/HH. (Moeller et al., 2013, p. 435)

The international consensus document provided the impetus for this research study. Using evidence from studies that examine parent-to-parent support facilitates awareness of the components of successful support, identifies the needs and challenges of families, and enables differentiation of this support from professional or other provider-related supports. This is the second of a two-stage study that responds to the same question: “What are the constructs and components of a conceptual framework of parent-to-parent support for parents with children who are D/HH?” Henderson, Johnson, and Moodie (2014) used a scoping review methodology within the peer-reviewed literature to determine the constructs and components of a conceptual framework. The second stage of the study provides an opportunity to engage with experts, transfer knowledge between experts, and work toward a satisfactory consensus (Colquhoun et al., 2014). Experts are leaders and stakeholders in the field who have comprehensive and authoritative knowledge. Individual contributions and the tacit knowledge of experts who have learned from parents engaged in parent-to-parent

support, or are parents themselves, are important factors in addition to theory, literature, and research needed to develop a comprehensive conceptual framework (Colquhoun et al., 2014).

The conceptual framework described in this document and its precursor (Henderson et al., 2014) is an evidence-based model that identifies the constructs, components, and complexities of exchange in parent-to-parent support. For decision makers in Early Hearing Detection and Intervention (EHDI) programs, this conceptual framework has the potential to inform policy development and program evaluations.

Method

The findings from the scoping review of the literature led to the development of a structured conceptual framework of parent-to-parent support for parents with children who are D/HH (Henderson et al., 2014). The scoping review identified 39 peer-reviewed articles published from 2000 to 2014. Data were identified, extracted, and organized into libraries of thematic and descriptive content. The electronic Delphi (eDelphi) method satisfies the consultation and final component of the scoping review (Colquhoun et al., 2014). Using web-based survey software, an international panel of experts contributed to the framework through two rounds of mixed-method questionnaires. This study was approved by the Health Sciences Research Ethics Board at the University of Western Ontario, London, Ontario, Canada.

Scoping Review

A *scoping review* is defined as “a form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting, and synthesizing existing knowledge” (Colquhoun et al., 2014, pp. 2–4). Henderson et al. (2014) developed the original conceptual framework through the following initial stages of a scoping review: definition of the research question, identification and selection of the relevant studies, data charting, collation, summary, and a report of the results. Scoping review methodology (Colquhoun et al., 2014) recommends the inclusion of a final stakeholder consultation stage to obtain insights beyond those offered by the literature (Colquhoun et al., 2014; Levac, Colquhoun, & O’Brien, 2010).

eDelphi Method

The aim of this study was to guide the development of—not validate—the original conceptual framework. The Delphi methodology engages stakeholders to provide personal judgment and opinion about a topic using methods that promote a balanced viewpoint, anonymity, iteration, structured feedback, and an aggregation of the group response to arrive at a consensus (Skulmoski, Hartman, & Krahn, 2007). Participants in Delphi studies engage in multiple rounds of thoughtfully designed questionnaires

(Goluchowicz & Blind, 2011; Okoli & Pawlowski, 2004). After each round, the responses from the group are collated and interpreted, and the participants are provided with summarized information to communicate various stakeholder positions (Balasubramanian & Agarwal, 2012; Okoli & Pawlowski, 2004). The sequential online questionnaires produce rich data because the respondents participate repeatedly and may adjust their responses on the basis of group feedback (Balasubramanian & Agarwal, 2012).

Several investigators have used this method in family-related studies, such as defining parenting strategies to help parents reduce the risk of their children developing depression and anxiety disorders (Yap, Fowler, Reavley, & Jorm, 2015), developing an instrument to measure parental child discipline behaviors (Runyan et al., 2009), and reaching a consensus on important elements of measuring participation in everyday life for children who need or use power mobility (Field, Miller, Jarus, Ryan, & Roxborough, 2014). The Delphi method is appropriate for the present study because there is incomplete knowledge about the constructs and components of parent-to-parent support for parents with children who are D/HH. This study used a modified Delphi technique with a structured first round on the basis of our review of the literature.

The Delphi method was modified by engaging experts through a web-based platform (SurveyMonkey). Referred to as eDelphi, the process provides a cost-effective approach for international participation (Gill, Leslie, Grech, & Latour, 2013; Tume, van den Hoogen, Wielenga, & Latour, 2014).

Mixed Methods

The eDelphi methodology used quantitative and qualitative elements in an integrated mixed-methods research design (Sandelowski, 2014). Mixed methods occurred during the collection and analysis of data. Qualitative and quantitative methods were used to collect data during Round 1 and Round 2. During each interpretation phase, the data were blended to compare and confirm results (Caracelli & Greene, 1993; Sandelowski, 2000). Although consensus is typically conceptualized and represented numerically, consensus can also be assessed by comparing and interpreting qualitative data (Sandelowski, 2000).

Panel Selection

Recruitment for Round 1 used a purposive selection strategy in which the investigators identified 100 leaders in provision or research in the area of parent-to-parent support for parents of children who are D/HH and have disabilities from the scoping review. Stakeholders with knowledge about parent-to-parent support in the field of hearing, speech-language pathology, or childhood disability were selected from research networks, nongovernmental institutions, national nonprofit organizations, individuals who self-identify as Deaf, and parents. The merits of each candidate were debated with an aim toward heterogeneity, as required in Delphi studies (Goluchowicz & Blind, 2011). A

total of 31 potential participants were selected because of their diverse backgrounds in the international community. Experiential knowledge and competency in parent-to-parent support by our participants enhanced the reliability of results (Goluchowicz & Blind, 2011). Participants resided in one of the following nine countries: Australia, Austria, Belgium, Canada, Germany, Israel, South Africa, the United Kingdom, and the United States. Panel diversity was sought to balance stakeholder representation, which is beneficial to avoid the issue of self-interest (Ecken, Gnatzy, & von der Gracht, 2011).

The selection of 31 experts allowed for possible attrition while working to maintain an appropriate heterogeneous sample size and meet appropriate eDelphi participant size recommendations (Balasubramanian & Agarwal, 2012; Bardecki, 1984; Okoli & Pawlowski, 2004). The eDelphi group size does not relate to statistical power, but adequate participation is essential for the establishment of good transferability of results or for the extent to which the responses can be generalized (Holloway & Todres, 2003).

Privacy and confidentiality may be precepts of a Delphi study, and the SurveyMonkey web-based platform assured anonymity in each phase. Round 2 included the question, "Did you participate in Round 1?" to help confirm purposeful sampling practices.

Questionnaire Development

The questionnaire aimed to assess the comprehensiveness, clarity, and applicability of the conceptual framework of parent-to-parent support for parents of children who are D/HH (Henderson et al., 2014). Intended to guide researchers, parents, and decision makers in EHDI programs, the questions directed participants to evaluate the ease of understanding, readability, and functionality of the model. Using the original design to guide the collection of qualitative and quantitative data, the questionnaire compartmentalized each element of the framework. Participants viewed the image of the original conceptual framework and then received questions that led participants to methodically consider every component of the model. Participants addressed conceptualization and design, evaluated labels and definitions, assessed wider construct groupings, and reflected on future functionality. See the online supplemental materials (Supplemental Text A and B) for Round 1 and 2 Questionnaires.

During both rounds, the questionnaire used a consistent 11-point Likert scale (0 = *strongly disagree* to 10 = *strongly agree*) to assess participants' opinions. Likert scales are a common rating format for surveys to assess judgments of an individual or group (Barnette, 2010). The scale gave the participants the option of a neutral response (5 = *neither agree nor disagree*) and also allowed the researchers to assess responses on a scale that was analogous to a percentage rating scale. In Round 2, the questionnaire used the explicit closed-question technique as an additional qualitative method (Roulston, 2008a). Participants were limited in their response choice and were asked to choose between "A" or "B." The closed questions were intended to confirm consensus on labels. Open-ended questions provided the

opportunity to collect qualitative data. After every Likert scale or closed question, the questionnaire used open-ended questions designed to allow participants to elaborate on their opinions and provide the panel members with the opportunity to initiate topics (Roulston, 2008b).

Round 1

The Round 1 questionnaire was distributed and returned between November and December 2014. Thirty-one invited participants were sent a brief introduction to the study and informed about the aim and nature of the study in a targeted e-mail message with an invitation to participate and a link to the eDelphi questionnaire. Participants were presented with an overview of the findings from the scoping review of the literature and the resulting initial informational graphic (Henderson et al., 2014). The graphic depicted the constructs and components of the framework on the basis of evidence resulting from the review of the literature. A total of 21 respondents from seven (or more) countries provided feedback in Round 1, which meets the recommended criteria of a 70% response rate (Keeney, Hasson, & McKenna, 2006). Four individuals did not identify their country of residence on the questionnaire. The researchers hypothesize respondents excluded country of residence because it could be an identifier and compromise anonymity. The 70% response rate supports the purposeful sampling of respondents who may have been motivated by the subject and recognized the need for this conceptual framework to enhance EHDI programs and support parents.

Round 2

Two panel members independently identified one additional expert each and requested permission to share the Round 2 survey. Given the two experts' keen interest, the researchers granted permission. One participant from Round 1 could not participate in Round 2 and informed the researchers. Therefore, 32 experts were invited to participate in Round 2. The questionnaires were distributed and returned between March and May 2015. As per Delphi methodology, the participants were provided with summarized diverse opinions and comments, collated judgments, and statistical data from the first round. A revised survey was developed on the basis of the participants' quantitative and qualitative feedback.

During Round 2, 17 participants from five (or more) countries completed the full questionnaire. This is consistent with the literature that states that it may be difficult to maintain participation over time in Delphi studies (Keeney et al., 2006). However, 17 participants meet the criteria, which recommends 10 to 18 experts for a Delphi panel (Balasubramanian & Agarwal, 2012; Bardecki, 1984; Okoli & Pawlowski, 2004). Please refer to Table 1 for an overview of the research process.

Results

The interested reader is referred to Henderson et al. (2014) to obtain an in-depth understanding of the original

conceptual framework. The conceptual framework of parent-to-parent support for parents of children who are D/HH was based on English-speaking literature from countries where EHDI programs are established. The general visual infographic design of the revised framework has remained unaltered from Henderson et al. (2014). Figure 1 provides the revised conceptual framework of parent-to-parent support for parents of children who are D/HH. The constructs and components are presented in a closed helix visual design with the supporting and learning parents at opposite curves. The "learning parent" is characterized as having a child recently identified as D/HH. The "supporting parent" has the lived experience of having a child with hearing loss. The helix represents the exchange of information between the parents. Two descriptive words—*connectedness* and *contribution*—describe the underpinnings of the relationship. Three overarching themes (constructs)—well-being, knowledge, and empowerment—are mirrored in the roles of the supporting and learning parents. In the flexure of the learning parent, arrows indicate that relationships exist between the defining constructs, namely, that knowledge and well-being promote empowerment and empowerment and knowledge increase well-being. Under each construct, broad descriptive elements (components) are found on the supporting parent's spiral. Last, specific key elements (components) itemize specific parental needs of the learning parent.

The goal of the present work was to achieve a consensus on labels, definitions, constructs, relationships, clarity of the informational graphic, and potential usability. High consensus was achieved on many aspects of the initial conceptual framework at the end of Round 1 (mean agreement ranged from 75% to 95%). Yet, as Goluchowicz and Blind (2011) point out, comments of dissensus in qualitative feedback highlight important issues and provide valuable information (Goluchowicz & Blind, 2011). Many stakeholders provided opinions with strong rationales in the qualitative data that differed from the quantitative consensus, and these opinions were brought back to the panel in Round 2 (Bolger & Wright, 2011).

The labels and their associated definitions for the revised conceptual framework are provided in Table 2. These definitions supplement the infographic and are referred to in the rest of the document. The remainder of the results section provides details about each component or construct illustrated in the infographic (see Figure 1) and defined in Table 2.

Parent-to-Parent Support

Participants gave feedback on the appropriateness of the phrasing *parent-to-parent support*. There was strong sentiment (91%) among respondents (Round 1, $n = 21$) that *parent-to-parent support* is an appropriate descriptor. No respondent disagreed with the descriptor. One participant stated, "I think parent-to-parent support actually describes about 90% of the people involved in p2p [parent-to-parent] support (others are immediate and extended family members), so it is

Table 1. Overview of the research process.

Research Activity	Timeline
Phase 1	
Ethics approval received	September 2014
Developed 37 QUAN statements using an 11-point Likert scale (<i>strongly disagree</i> to <i>strongly agree</i>) and 14 QUAL open-ended questions	September–October 2014
Collected QUAL and QUAN data	November–December 2014
Analyzed QUAL and QUAN data	January 2015
Phase 2	
Developed six QUAN statements using an 11-point Likert scale (<i>strongly disagree</i> to <i>strongly agree</i>), 11 QUAN closed “A” or “B” questions, and 33 QUAL open-ended questions	February 2015
Collected QUAL and QUAN data	March–May 2015
Analyzed data	May–June 2015
Decided to close study after two rounds	May 2015
Overall findings and interpretations	June 2015

Note. QUAN = quantitative; QUAL = qualitative.

an accurate term.” As an alternative, participants suggested *family-to-family support* as a more appropriate descriptor.

Although I think the term works, you may want to consider family-to-family support. Family-centered practice principles emphasize a family systems approach. Thus, the title change might reflect that broader focus on the family. In addition, many children experience parenting beyond the traditional “parent,” so the broader term of family-to-family might also capture non-traditional parenting practices.

The authors agree that *family-to-family support* may have been a good alternative had the review of the literature included grandparent, adolescent, and sibling data. However, the literature review did not encompass all family member perspectives, and one respondent stated the following:

I agree entirely with your reasoning and explanation as above, but just have a very slight reservation in that sometimes the primary carers may well be the grandparents or others with parental responsibility.

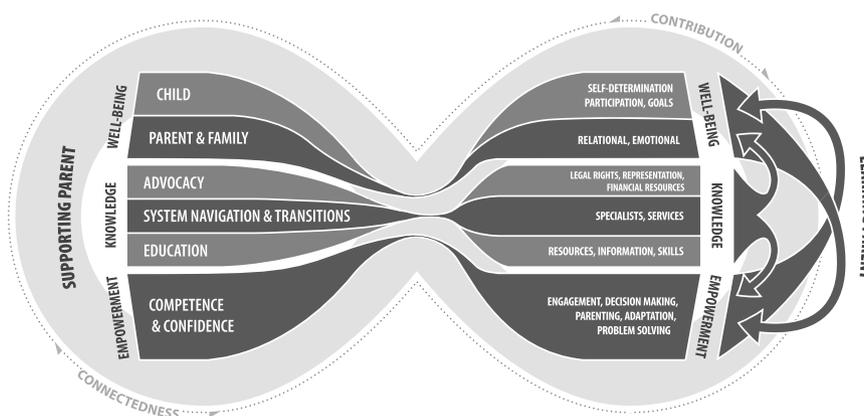
However I think as long as we acknowledge that that can be the case, I think this phrasing is the best.

The scope of the literature review focused on parents with children who are D/HH or have other disabilities and did not include extended family voices. Given the scope of the literature review, high respondent consensus in Round 1, and thoughtful participant responses together with strong quantitative consensus (95%) in Round 2, *parent-to-parent support* appears to be the appropriate descriptor for this framework.

Supporting Parent

The majority of respondents (Round 1, $n = 21$) agreed (87%) with the term *supporting parent*. As an alternative, respondents provided a strong rationale for *mentoring parent* as a better descriptor. With this suggestion, the authors returned to the participants in Round 2 and provided the opportunity to further consider the merits of the descriptors *mentoring parent* or *supporting parent*.

Figure 1. A revised conceptual framework of parent-to-parent support for parents of children who are Deaf or hard of hearing.



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Table 2. Terms and definitions of the revised conceptual framework of parent-to-parent support for parents of children who are Deaf or hard of hearing.

Term	Definition
Supporting and learning parent	
Supporting parent	a coaching, nurturing and encouraging parent who has the lived experience of a child with hearing loss
Learning parent	a parent new to or inexperienced in a situation of raising a child who is D/HH (e.g., the parent may have a child recently diagnosed as D/HH or may be experiencing a transition in the child or family's life)
Contribution and connectedness	
Contribution	community relationships (D/HH role models, D/HH community and Deaf culture, peers, social groups, family members), engagement and development through the sharing of ideas, information and resources
Connectedness	the affirmation, validation, comfort, and sense of belonging found in the emotional connection of sharing of social identity, anecdotal and life stories
Construct 1: Well-being	
1A: Child well-being	
Participation	the child's involvement in hearing and Deaf communities, leisure and extracurricular activities, daycare/school, and ventures with family and friends
Self-determination	for the child who is D/HH: self-motivation, positive self-perception, and meaningful relationships
Goals	language and communication outcomes, social and psychosocial aspirations and educational and employment objectives and achievements
1b: Parent and family well-being	
Emotional support	offers psychological benefit such as coping, acceptance, hopefulness, self-reliance and confidence, readiness to engage in response to potential grief, loneliness, vulnerability and perceived stigma
Relational support	well-being related to family functioning. Family functioning includes bonding with the child, family and parental cohesiveness, and communication between family members. Community interaction is involvement in community and cultural networks, friends and religious institutions.
Construct 2: Knowledge	
2A: Advocacy knowledge	
Legal rights	laws, regulations, legislation and government policies related to human rights, child's rights, and special education laws
Financial resources	financial assistance, insurance, government funding, entitlements and not-for-profit or voluntary sector supplements
Representation	peer advocate, parental consultant, and advisor at the community, regional, and national levels
2B: System navigation and transition knowledge	
Specialists	support the parent's knowledge during system navigation and transitions to coordinate care with specialists, collaborate with stakeholders, provide a roadmap of care, and facilitate understanding of the role of the specialist(s)
Services	community resources, health care, school, legal and regional services
2C: Education knowledge	
Information	providing accurate, well-balanced, and comprehensive information regarding technological and research advancements, and educational, communication, and assistive device options
Skills	skill-based instruction and support, such as sign language and device-appropriate technological skills, as a supplement to specialized services and support
Construct 3: Empowerment	
3A: Confidence and competence	
Adaptation	component of parent-to-parent support that helps with adjustment, acceptance, motivation, hopefulness, resilience, learning, and optimism
Engagement	component of parent-to-parent support that helps with a parent's ability and readiness to optimize their parental role and engage in their child's habilitation process
Decision making	component of parent-to-parent support that provides access to knowledge and resources, and the opportunity to cultivate ideas for informed choice and decision making
Parenting	component of parent-to-parent support that provides practical parenting skills (e.g. teaching their child to safely cross the street), offers parenting advice to improve parent-child interactions and encourages responsive parenting to support the child's communication development in daily life
Problem-solving	component of parent-to-parent support that empowers parents to trust their coping abilities and acquire problem-solving skills specific to a child who is D/HH

Note. D/HH = Deaf or hard of hearing.

Participants provided varying rationales for *mentor-parent*. One respondent stated, “For being a mentor special teaching, supervision and guidance by professionals is included and not only experience. So the phrasing ‘supporting parent’ is not appropriate, if more than experience is [required].” Another participant expressed the following: “You are right, that all parents who have a child with a hearing loss have a lived experience. Why I am undecided [is in] regards to the point that a lived experience alone is not enough to become a supporting parent.” Another commented, “I would prefer a term including ‘mentor’ (e.g. parental mentor), because only the experience isn’t enough to convey information in an ‘unbiased manner’ like the JCIH [Joint Committee on Infant Hearing] (2013) demands.”

Respondents provided strong rationales for *supporting parent* as well. One respondent noted, “I prefer ‘supporting’ since ‘mentor’ is often defined or understood as a hierarchical relationship.” Another participant stated the following: “I prefer supporting parent because in a sense it is broader. The term mentor comes with some level of expectations, possibly implied training, etc.” Last, one panel member commented, “I am sensitive to the comment that was made suggesting ‘parents are both supporting and learning throughout their [...] experience’. Mentor suggests that one parent knows more than the other. Might a term such as ‘experienced parent’ be more descriptive?”

The respondents acknowledged that an experienced parent has the lived experience of a child with hearing loss and may also be characterized as someone who is teaching, modeling, encouraging, and mentoring.

Learning Parent

The opinion among respondents (Round 1, $n = 21$) was that *learning parent* is the most appropriate descriptor for the parent who has a child who is D/HH and is seeking support from an experienced parent with a child who is D/HH. The alternative label *novice parent* was suggested. One comment included the following: “I think that Learning Parent captures the notion of a parent learning new information and skills, whereas Novice Parent does not seem to include experienced parents who are in a new situation.” Other respondents stated, “I like the definition of ‘novice parent’ more than the term itself” and “I’m not completely sold on the descriptor Novice although I like the definition. I almost would just leave this as Parent.” One panel member noted the following:

The word “novice” makes me think of someone that doesn’t really have any current skillsets in the given context. I would argue that “new” parents of Deaf kids still come to the table with inherent expertise and skillsets that will serve them well: love, understanding their child in the holistic context, etc.

The comments provided about the descriptor *learning parent* included, “I like this term as I think we move between being supporting parents to learning parents constantly through the life of our child” and “I like the neutrality of

‘learning parents,’ but believe that they are not the only learners in the process.”

Parents are lifelong learners. In this context, a learning parent is inexperienced in the situation of raising a child who is D/HH or in an emerging situation in the child’s life. The outside arrows in the conceptual framework indicate the fluidity and movement as parents’ roles evolve and change. A respondent stated, “While I act as an informal mentor to new families, I receive support myself from parents whose children are older than mine in times of transition.” In the continuum of parent-to-parent support, parents may simultaneously exist as both the learning and supporting parent throughout their child’s life.

Contribution (Previously Mutuality)

The original framework used the descriptor *mutuality* to describe the exchange of information, ideas, and resources with peer mentors and role models. Respondents (Round 1, $n = 21$) agreed that *mutuality* was a fairly appropriate term; however, alternative labels were suggested, including *commonality*, *collaboration*, *shared contribution*, and *connection*. Respondents noted, “I would stress the active contribution of both parties aimed at sharing benefits from the relation” and “Contribution seems uni-directional . . . mentor to learner, when the impact may be bi-directional . . . that may be an advantage to the term mutuality—however, I am not sure that mutuality is very clear.”

Participants indicated that both the descriptor label and definition required clarity. Contribution is the active (or external) expression of parent-to-parent support. The contribution comes from a participatory and action-oriented community that shares information, ideas, and resources. Community relationships develop between learning parents, supporting parents, D/HH role models, members of the Deaf community and culture, peers, community members, and family members. The developments arising from this community can effect change at the local, regional, and national levels.

Connectedness

Participants (Round 1, $n = 21$) suggested that *connectedness* is an appropriate descriptor (87%) that encompasses social identity, affirmation, validation, comfort, and sense of belonging when raising a child who is D/HH. The respondents also suggested the alternative label of *connection*. Some participants commented on the descriptors *connectedness* and *connection*: “I’ve always found at least some form of connectedness in parent to parent support groups I’ve participated in!”; “Connectedness implies to me more than a connection—it implies also an emotional interaction between participants.” One participant stated the following:

In my view, social identity is the overarching concept under which affirmation, sense of belonging and social kinship should be placed. It is the person’s affiliation with a social identity that opens up spaces for affirmation, belonging and social kinship. So, I would dismiss the term “connectedness” altogether.

The respondents provided strong rationales for the best descriptor to identify the emotional interaction in peer parental support. The authors assert that the conceptual framework as a whole responds to *social identity*. Social identity is grounded in the idea that the parents in peer parental support are raising children who are D/HH. *Connectedness* describes the emotional connection because a shared social identity may not be the only reason to participate in parent-to-parent support. Therefore, in contrast to *contribution*, which is an external representation of parent-to-parent support, *connectedness* describes the emotional connection and sharing of anecdotal life stories and social identity between parents who share the lived experience of raising a child who is D/HH. Three overarching themes (constructs) are (a) well-being, (b) knowledge, and (c) empowerment and are mirrored in the roles of supporting and learning parents (see Figure 1).

Construct 1: Well-Being

Well-being is generally understood as the dynamic aspects in one's personal and relational life that affects overall quality. Parent-to-parent support contributes to child and parent and family well-being. The external arrows (see Figure 1, beside the descriptor *learning parent*) indicate knowledge, and confidence and competence improve well-being. See Figure 2 for a graphical representation of the well-being construct.

Construct 1A: Child Well-Being

With input from the consultation process, the learning parent needs support related to child (a) self-determination, (b) participation, and (c) goals.

Self-determination (formally "autonomy"). Although some (79%) of the respondents (Round 1, $n = 21$) felt that the term *autonomy* adequately described decision making, stress-related coping strategies, and persistence, they also suggested alternative labels such as *self-determination*, *independence*,

self-advocacy, *self-efficacy*, and *self-reliance*. One respondent stated, "Self-determination (to me) encompasses more than autonomy—it includes a sense of understanding of the world around oneself and the willingness and ability to make informed decisions, even in the case of a child."

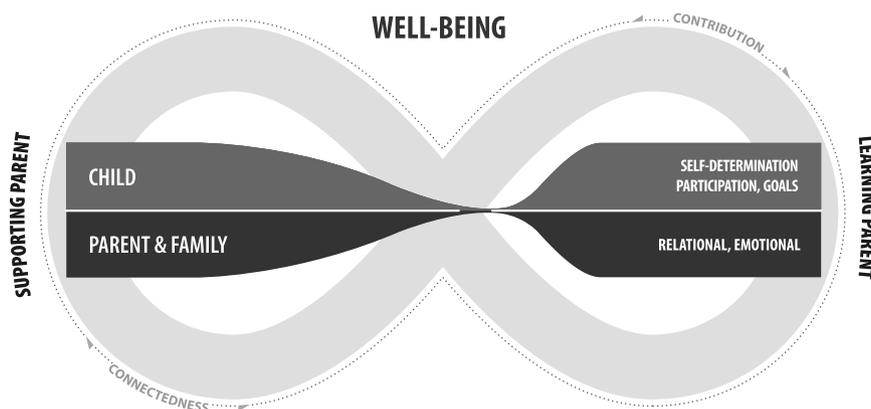
On the basis of the self-determination theory literature for children who have disabilities, self-determination is composed of a triad that includes competence, autonomy, and relatedness (Palmer et al., 2012; Poulsen, Rodger, & Ziviani, 2006). Professionals and parents can use strategies related to self-determination theory to help children through self-motivated engagement in activities, positive self-perceptions of feeling competent and confident, and connections with others for psychological well-being (Poulsen et al., 2006). For example, a child exhibits self-determination when he independently removes his own hearing aids at night and puts them away appropriately. In Round 2, the respondents agreed (89%) that *self-determination* is the appropriate descriptive term.

Participation. Respondents (Round 1, $n = 21$) strongly agreed (94%) that the term *participation* described involvement in hearing and Deaf communities, leisure and extracurricular activities, day care or school, and ventures with family and friends. *Participation* is the appropriate descriptor.

Goals. Results from Round 1 indicated that some (86%) of the respondents ($n = 20$) agreed that *goals* described child well-being as it relates to language achievement, communication outcomes, and employment objectives. However, some respondents provided alternatives to the descriptor *goals* and suggested *aspirations*, *planning*, *goal setting*, *positive perspectives*, *outcomes*, *planning*, and *future orienting*. In Round 2, the respondents ($n = 18$) chose between the descriptors *outcomes* (44%) and *goals* (56%). One participant noted the following:

The two terms are very different in meaning and their appropriateness depends upon the processes

Figure 2. A conceptual framework of parent-to-parent support: Construct 1: constructs and components of well-being.



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which should be emphasized. “Outcomes” implies achievement, regardless of the aspiration, intention, the journey itself. “Goals” is open about whether or not they are achieved but, crucially, for me, emphasizes the aspiration, desire and experience more than the thing which is attained. Goals seems to me the better term by far.

Other respondents stated, “Because this relates to well-being, outcomes seem clearer”; “Often parents talk in terms of desired outcomes”; and “I know what you mean but usually parents do not have such structured goals for their children.” The respondents stated that a goal is something that a child is trying to do or achieve, and an outcome is something that happens as a result of an activity. *Outcome* is used in education and health care plans and clinical care practice. For children who are D/HH, an intervention, interaction, or treatment may be successful or revised based on the clinical outcome. This framework is ultimately for parents involved in peer support. An organization may want to measure an outcome in parent-to-parent support, but from a parental perspective, *goals* best reflects the child’s journey and is a term parents may prefer.

Construct 1B: Parent and Family Well-Being

For parent and family well-being, the learning parent(s) need relational and emotional support. In the first version of the conceptual framework (Henderson et al., 2014), adaptational support was believed to be a primary influence on parent and family well-being. Although some (84%) of the stakeholders (Round 1, $n = 20$) agreed that adaptation is a vital component for productive family relationships and an underpinning component of adapting to surfacing and challenging situations, they recommend that *adaptation* is better suited to Construct 3: Empowerment/Competence and Confidence. Therefore, the components of parent and family well-being in the second version of the framework include (a) relational support and (b) emotional support.

Relational support. Most (95%) of the respondents (Round 1, $n = 20$) agreed that the descriptor *relational support* described bonding with the child, family functioning, family and marital/conjugal cohesiveness, interaction, and communication between family members. With qualitative input from Rounds 1 and 2, revisions were made to the definition.

Emotional support. Most (95%) of the respondents (Round 1, $n = 20$) agreed that the descriptor term *emotional support* described parent-to-parent support that provides psychological benefit. Suggestions were incorporated that resulted in a revised definition, which indicated that emotional support offers benefits such as coping, acceptance, hopefulness, self-reliance, confidence, and readiness to engage in response to potential grief, loneliness, vulnerability, and perceived stigma.

Construct 2: Knowledge

The framework of parent-to-parent support illustrates that empowerment and well-being advances knowledge.

International consultation refined the constructs of knowledge in the infographic. *Knowledge* (see Figure 3) includes (a) advocacy, (b) system navigation and transitions, and (c) education.

Construct 2A: Advocacy

With input from the consultative process, the learning parent can benefit from the lived experience of supporting parents in terms of advocacy primarily regarding, but not limited to, (a) legal rights, (b) representation, and (c) financial resources.

Legal rights. The respondents (Round 1, $n = 21$) reached a consensus (91%) on this descriptive term, and although other descriptors, such as *regulation* or *legislation*, were suggested, the investigators believed that *legal rights* is a better descriptor that parents in most countries may understand.

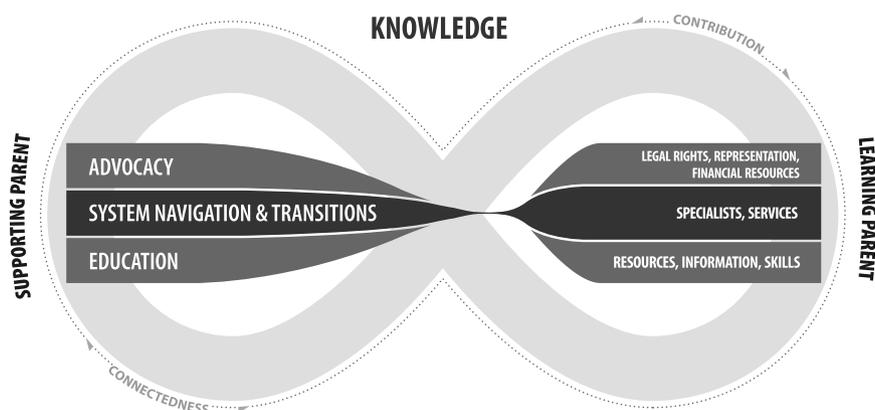
Representation. Respondents (Round 1, $n = 21$) reached a consensus (83%) that *representation* was an appropriate descriptor. Comments indicated that the term *representation* as a component of advocacy may better describe the continuum of advisory engagement of the supporting parent to the learning parent. On the basis of respondent input, revisions were made to the definition of *representation*. *Representation* refers to peer advocate(s), parental consultant(s) and/or advisors at the community, regional, and national levels. However, it should be noted that some qualitative data revealed a potential preference for the descriptive term *advocate*. Some respondents stated the following: “Advocate definition—one stands in the place of or on behalf of” and “I think the terms have different connotations at different levels and for different purposes. Advocacy has a role, but depending on the end goal, the term representation may be less adversarial and more likely to enhance collaboration to support the child and family.” On the basis of respondent input, *representation* was the selected term, and revisions were made to the definition.

Financial resources (previously “funding”). Respondents ($n = 21$) in Round 1 demonstrated a strong consensus (87%) for the descriptor *funding*. However, written comments recommended *financial services*, *financial support*, *funding and resources*, *provisions*, and *entitlements* as better descriptive terms to *funding*. Most (89%) of the experts (Round 2, $n = 16$) agreed that *financial resources* was the best descriptor.

Construct 2B: System Navigation and Transitions

The respondents suggested that the magnitude and impact of *transitions* on families raising children who are D/HH placed this descriptor term at the level of a construct deserving placement as a main topic heading with *system navigation*. One respondent noted that “special attention may be warranted to transitional stages due to the difficulty parents’ encounter as kids move across systems/providers.” The experts emphasized that empathetic and action-oriented peer support is crucial during times of system navigation and transition.

Figure 3. A conceptual framework of parent-to-parent support: Construct 2: constructs and components of knowledge.



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Specialists (previously “professionals”). A majority (89%) of the panel (Round 1, $n = 21$) agreed that *professionals* was an appropriate descriptor term; however, the respondents also suggested the descriptor *providers*. In Round 2, written comments responded negatively to both descriptors, *professionals* and *providers*. Some respondents stated the following: “[I] do not like provider . . . we are professionals”; “Providers seems appropriately broad,” “Providers does not (in my mind) capture the notion that the individuals are specialists”; and “Professionals can be disconnecting.”

As an alternative to *professionals* and *providers*, one respondent stated, “I like ‘specialists’ as this indicates a high level of knowledge. A professional has earned a degree or certification, but may not be a specialist. With our low-incidence population I prefer ‘specialist’ which, I think, implies the person is a professional.” A specialist is a person who concentrates on a particular subject or activity and is highly skilled in a specific field. The role of the supporting parent in a parent-to-parent framework is to assist with system navigation and transitions and provide awareness of specialists and the service provision of specialists (professional or otherwise).

Services. Most (94%) of the participants (Round 1, $n = 21$) rated the term *services* as appropriate. The following comment suggested the inclusion of services outside the D/HH community:

Other types of (not necessarily professional or Deafness-specific) support systems, such as organisations for persons with disabilities, self-help communities, religious organisations, etc. Unless you consider these to be “outside the system”. But still, I think “knowledge” about these resources should be included somewhere in the model.

The supporting parent has the knowledge of services and community resources to assist parents with system navigation and transitions.

Construct 2C: Education

Information. Participants (Round 1, $n = 21$) noted that *insight*, *context*, and *experience* are just as important as information. The authors agreed that life experience is invaluable, and the contribution that represents life experience is included in the outside arrows of the infographic labeled “Contribution and Connectedness.” *Information* received high agreement (91%).

Skills. *Skills* was considered an appropriate descriptor (86%) by participants (Round 1, $n = 21$). Some respondent comments provided on the descriptors *training* and *skills* include the following: “Training does not convey partnership in my mind”; “I like the term ‘skills’ as acquisition of skills is the outcome for the novice parent. Conversely, training seems to me to be the role of the mentor”; “I don’t see mentor parents as important providers of skills or training; I see their value in provisions of other support. I am not comfortable, actually, with the inclusion of either term in the model.” Participants further stated that “I think the term skills is broad enough to cover the intent yet specific enough to communicate the parent is gaining new skills” and “A skilled parent may transition into the role of mentor parent with appropriate training/supports.” One respondent expressed the following:

I think for me, you need to clearly keep separate what parent-to-parent support provides versus what a professional with a skillset provides. For example, I don’t think most parent to parent models TEACH these skills as much as provide WHERE a family can get access to expertise in these things for example: sign language acquisition (sign language instructors) and hearing aid use (audiologist) would be in the purview of the professional service provision, NOT parent-to-parent support. Though parents might talk about WHERE they can get these services [. . .] I think there is an imperative line that needs to be drawn about what parent to parent support IS and what it is not!!!

In the peer-reviewed literature, parents with children who have hearing loss are looking for training to develop their skills in important communication areas and seek out best-practice training from clinical care specialists (Hardonk et al., 2011; Jamieson et al., 2011). However, parents indicate that the reality of their situation is that their child may be ineligible or on a waitlist to receive specific instruction or specialized service may be unavailable (Jamieson et al., 2011). Therefore, parents may not have access to specialists to receive training or practice skills, and this highlights a gap in service delivery. When there is a gap or barrier in service delivery, such as a family placed on a waitlist to learn sign language, the family has an unmet need that requires attention. Parents want the service, and if they cannot receive it from specialists, they will seek direct guidance from a peer to practice skills and promote their child's communication as an interim solution when specialists and specialized services are unavailable. Supporting parents may have the skills knowledge to offer a learning parent when there is an unmet need in service delivery.

Construct 3: Empowerment

Experts in the consultation process agreed that parent-to-parent support positively influenced parental empowerment. *Empowerment* (see Figure 4) is a construct influenced by knowledge and well-being. Expert judgment agreed that parent-to-parent support provides competence and confidence in (a) engagement, (b) decision making, (c) parenting, (d) problem solving, and (e) adaptation.

Construct 3A: Confidence and Competence

Engagement, decision making, parenting, and problem solving. On the basis of expert feedback (Round 1, $n = 21$), the highly rated descriptors *engagement* (95%), *decision making* (92%), *parenting* (91%), and *problem solving* (94%) were accepted with revised definitions (see Table 2).

Adaptation (includes previous label "self-awareness").

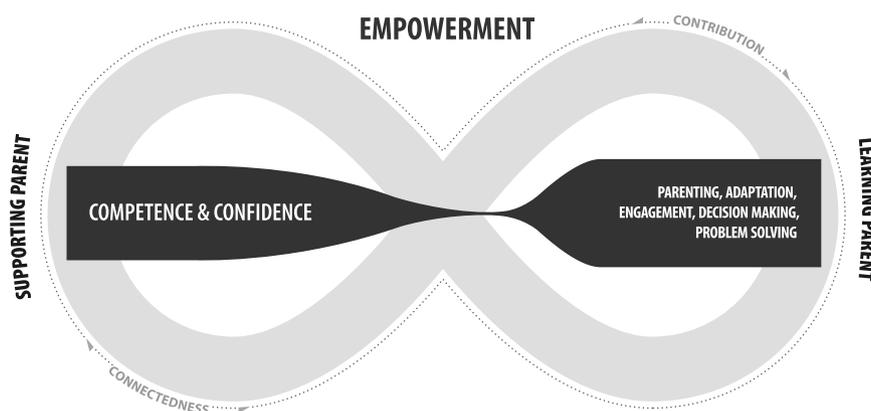
The term *adaptation* described a component of parent-to-parent support that helped with adjustment, acceptance, motivation, hopefulness, resilience, learning, and optimism. In the original infographic (Henderson et al., 2014), *adaptation* was positioned within parent and family well-being. Many participants suggested that the adaptation component was more appropriate to include in *competence and confidence*. In Round 1, a respondent noted that self-awareness "is a necessary condition in the process of developing and/or having competence & confidence." The change to combine self-awareness and adaptation as one component of empowerment received consensus. Participants (Round 2, $n = 16$) chose between *adaptation* and *self-awareness* and preferred the descriptor *adaptation* (75%).

The Conceptual Framework as a Model

One way to understand the conceptual framework of parent-to-parent support is through a model that can promote common understanding. This model could be used in audiology practice and audiology educational curriculum to develop a common language to explain the role of parent-to-parent support. This model may also help guide change to improve parent-to-parent support for parents of children who are D/HH. A model can help decision makers understand context and content better and facilitate interventions (Exworthy, 2008). Using the model as a problem-solving approach, participants were asked the following: "How certain are you that this revised conceptual framework has the ability to serve as a model for parent-to-parent support for parents of children who are Deaf or hard of hearing?" Of the 21 respondents, 20 agreed with significant certainty (Round 1, 85%) that the conceptual framework has the ability to serve as a model for parent-to-parent support for parents of children who are D/HH.

Furthermore, the respondents were certain (Round 1, 89%; $13/21 \geq 90\%$ certain) of the applicability of the

Figure 4. A conceptual framework of parent-to-parent support: Construct 3: constructs and components of empowerment.



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framework for their or their colleagues' work. Many respondents gave a response similar to the following: "It gives the user a sound overview on the most important variables that have to be considered when working in the context of parent-to-parent support." Comments of uncertainty generally focused on environmental factors of parent-to-parent support. One respondent stated, "Parents shape meaning-making with regard to Deafness and hearing loss within a discursive context and this is not well-illustrated or documented." The authors agree that the contextual piece of the conceptual framework requires additional investigation.

Models must be appropriately organized and designed to be effective. The respondents agreed (Round 1, 16/20 \geq 80%) that the conceptual framework was appropriately organized and designed. Some respondents noted that it was "clear and comprehensive" and a "promising model." The respondents offered suggestions to revise the model to better reflect the relationship between the supporting and learning parents. The need for further clarification concerned the representation of the arrows outside of the helix. The outside arrows illustrate three fluid movements and concepts: (a) the parents are grounded in a relationship of connectedness and contribution, (b) the learning parent may assume the role of the supporting parent, and (c) the parents may alternate between roles of supporting and learning parents during periods of transition throughout their child's life. The conceptual framework was updated to reflect these suggestions.

The research is ultimately aimed to establish and demonstrate a foundation for parent-to-parent support. The respondents stated with certainty (Round 2, 15/16 \geq 90%) that the conceptual framework was comprehensive and identified the components and constructs of parent-to-parent support for parents of children who are D/HH. The integrated mixed-method analysis strived to be accountable to both quantitative and qualitative data and to address suggestions for revision. The research aimed to carefully address recommendations, criticism, and approval.

A visual presentation of the framework in an informational graphic provided an opportunity for parents, experts, researchers, and others to be open to and reflective on the components of parent-to-parent support for parents of children who are D/HH. After completing the questionnaire, one respondent noted the following:

This exercise has me thinking so much about moments in my life of being supported and supporting other families. . . . So at the end of the day, there is a component of parent-to-parent support that I believe cannot be written about, researched, labeled, frameworked, or defined. It just is. Maybe it's the listening part, the laughter, the tears, the humor and the wine that just got me through to the next thing, the next day, etc. in this thing we are calling a "framework" it just is.

The knowledge gained through listening to experts express themselves in response to this study may frame possible discussion points for continued research about the

intangible spirit outside of a tangible framework when engaging in parent-to-parent support.

Other Important and Relevant Information Provided by Experts

The purpose of the eDelphi study helped confirm the vital importance of parent-to-parent support in the overall care of children who are D/HH. In addition to finding good consensus on the conceptual framework, the eDelphi study was successful in raising expert opinions on emerging topics about the environment of parent-to-parent support. The environment of support refers to the conceptual framework in practice and application, namely, how the framework may be used and implemented.

The analysis of the qualitative data identified a number of thematic concerns and suggestions outside the scope of the study. The experts' comments are summarized under the additional construct *environmental context*, and the components include (a) role of supporting parents, (b) organizational structure, (c) community support systems, and (d) social determinants of health. The advantage of including results outside the scope of the study includes continuing the parent-to-parent support discussion and highlighting future important areas for research.

Additional Construct: Environmental Context

The challenges of the role of the supporting parents, existing professional and community systems, and the social determinants of health are all too real and continue to affect the provision of parent-to-parent support. Put simply, the model cannot stand alone because of the context in which parent-to-parent support is provided. One respondent stated, "Parent-to-parent support is embedded within a large context of various support and provision of care mechanisms such as families, professionals, institutional, D/HH role models, existing community, etc. This could be made more apparent." This comment suggests that the influence of environmental factors affects how support is given and received. The participants expressed the importance of engaging with the framework in a parent-to-parent support environment. They argued that how support is given is necessary to understand what support is provided.

Role of supporting parents. Supporting parents assume evolving and nonstatic roles in a spectrum of parent-to-parent support. Many respondents recommended full or partial training of the supporting parent.

I might add the word "trained"—Supporting Trained parent. In order for Parent to parent support to be successful, I believe that there is some training involved in one's ability to be able to share one's story without bias, support in context to the supported family's needs, and skills in listening, knowledge of available resources etc.

Parents can assume many roles in the environment of parent-to-parent support. The respondents expressed beliefs that there may be two types of support in the "experienced

parent” dyad, namely, a trained parent (mentoring) or an informal parent (supporting). Emerging from this consultation process is the understanding that there is a continuum of trained and informal parents who provide support to learning parents. The respondents indicated that supporting parents require training to know when to refer families to various professional systems (audiology, psychiatry, or care coordinators) to ensure that families obtain comprehensive and evidence-based care. The limits and boundaries of the supporting parent were another concern. The respondents’ comments suggested that the supporting parent operate in a nonjudgmental, unbiased, trusting, respectful, honest, confident, holistic, credible, and unconditional way. Inclusive parent-to-parent support would consider cultural, spiritual, and religious contexts and help parents find support within self-identified communities. A theme of equality also emerged. Some participants commented that there is a hierarchy to this relationship; others responded that a hierarchy is disempowering and that parents participate in mutual mentoring. Future research would examine viewpoints on the roles, responsibilities, and relationships of the supporting and learning parents, including the ethical and legal considerations of the supporting parent as a key factor in C&FCC (Shaul, 2014).

Organizational structure. Organizational structure refers to the operational process, coordination, and supervision of parent-to-parent support. The respondents commented that successful parent-to-parent support requires professional and organizational oversight and support, namely, in the government or voluntary sector. However, in some cases, challenges may exist that impede the sustainability of parent-to-parent support. The issues relate not only to ensuring access to supporting parents across all degrees of impairment (mild to Deaf) but also to language and cultural diversity, including Deaf culture and geographic (rural, remote, and northern) locations. Organization-based parent-to-parent support may not have the appropriate processes and logistical or financial support to offer all families. Parent-to-parent support refers parents to specialists, partners with specialists and professionals, and provides adjunct care to parents. One participant commented that there is a disconnection between parent-to-parent support and professional systems.

P2P [Parent-to-parent] does not supplant what professionals bring to parents, and professionals should not look at [parent-to-parent] support as a threat and/or somehow taking over “their” job. When [there is] a clear framework of what parents DO provide each other, maybe then more professionals will not be gatekeepers and keep families from one another. i.e. “the family is not ready to meet other families.”

One respondent pointedly acknowledged that the model is not supportive to parents if parents are unaware of parent-to-parent support systems.

I think somehow it needs to address [and]/acknowledge how to facilitate this/how parents [are] connecting

with one another. What system needs to exist to make this possible? Many parents do not know how to find [and]/access other parents. Many audiologists do not help connect parents with one another.

Additional research may address concerns regarding educating professionals about the benefits of parent-to-parent support. The literature and experts refer to an outdated contextual atmosphere of service provision that provides medically focused care rather than a holistic child- and family-centered philosophy that recognizes and supports (financial and otherwise) formal and informal parent support as central to child and family well-being.

Community support systems. Community is a broad term to describe people who are connected to each other. A community of people may be connected by shared experiences or culture or by living in the same area. Community support systems are advantageous to a family requiring support because they provide cultural and language communication and encourage a community to rally in support of a family. Parent-to-parent support should recognize and continue to recognize and emphasize the importance of community systems, including cultural, kinship, and religious ties. Parents may prefer support outside of the social identity of raising a child who is D/HH.

Social determinants of health. The social determinants of health are factors that influence the health of a population (Mikkonen & Raphael, 2010). The conceptual framework does not account for social determinants of health factors, such as parental income, employment and job security, education levels, early childhood development, food (in)security, social exclusion and social safety networks, gender, race, disabilities, housing, and social status, among other important factors that affect parental and child well-being. Parent-to-parent support exists in a wider national and cultural system, and the social determinants of health may affect how parent-to-parent support is provided.

More work is required to understand the environment of support and how the interrelated environmental constructs interact with this model of parent-to-parent support for parents of children who are D/HH. Defining an environmental conceptual framework and the relationship with this model can help parents, health professionals, and organizations target what is needed before developing and organizing intervention programs of parent-to-parent support for parents of children who are D/HH.

Discussion

As parent-to-parent support is increasingly integrated in EHDI programs, best practice suggests that providers “ensure that all families have access to parent-to-parent support from other families of children who are D/HH [and] recognize the key role of parent-to-parent support in promoting social and emotional well-being for families” (Moeller et al., 2013, p. 430). Academic and nongovernmental institutions have identified the need to develop guidelines of

parent-to-parent support (Joint Committee on Infant Hearing, 2007, 2013; Moeller et al., 2013; Poon & Zaidman-Zait, 2014). The conceptual framework described herein is an evidence-based model that identifies the constructs, components, and complexities of exchange in parent-to-parent support.

The framework demonstrates the centrality of parent-to-parent support in EHDI programs and identifies parent-to-parent support as a tenet of C&FCC principles. In part, the functionality of the framework may inform C&FCC evidence-based decisions and provisions for appropriate, efficient, and effective resource allocation and program improvements. Participants stated, “We are constantly having to defend parent to parent support as an ‘add on’ to the journey as opposed to [an] ‘essential element’ so I think this model will give us the teeth to move parent to parent support into [a] systemic requirement”; “An advantage of the framework is that providers can better recognize what parents have to offer one another and the value of helping connect parents to other parents. I wonder if providers don’t necessarily recognize how important this is”; and “A parent-to-parent support conceptual framework has the potential for real-world organizational application in EHDI programs.”

There is an ongoing dialogue regarding the value of parent-to-parent support, and this framework acknowledges and reinforces the importance of this type of support in EHDI services. It serves as a tool and provides a problem-solving approach to develop, improve, or evaluate existing parent-to-parent support programs.

Strengths and Limitations

There are emerging possibilities and hope for parent-to-parent support in EHDI programs. The participants in this study are particularly invested in the quality of parent-to-parent support, and their tacit knowledge provided judgment and opinion not otherwise reported in the peer-reviewed literature. The eDelphi methodology provided an opportunity to engage in knowledge transfer and arrive at a deeper understanding of the constructs and components of this model. Revisions to the framework’s structure, constructs, terms, and definitions led to developing a more comprehensive model.

The strengths of the Delphi methodology included knowledgeable participants, international representation, and heterogeneity of participants. Many participants are involved in EHDI programs and may have had daily interactions with parents. They recognize the historic and evolving nature of parent-to-parent support in C&FCC philosophy and its role in organizations across countries. The integration of peer-reviewed literature and expert representation addressed academic, tacit, and experiential knowledge to co-create this conceptual framework.

The study had strong participation rates (Round 1 = 21; Round 2 = 17). However, equal participation for both rounds may have been obtained by securing assurance to participation before the study commenced (Balasubramanian & Agarwal, 2012; Okoli & Pawlowski, 2004). The researchers

decided to protect the voluntary nature of the study and participant anonymity in lieu of required participant commitment.

Given the realities of the participants’ diverse leadership roles and regional, national, and language differences (for those participants who acknowledged English was a second language), the terms did not always reach a quantitative consensus. For many “A” or “B” closed questions, the respondents did not achieve a consensus on the labels. To illustrate, when asked to choose between *supporting parent* or *mentoring parent*, respondents indicated a split in preference for *supporting parent* (44%) and *mentoring parent* (56%). There was a similar response when asked to choose between *learning parent* (50%) or *novice parent* (50%). This reoccurred with *connectedness* (50%) and *connection* (50%), and *goals* (56%) and *outcomes* (44%). Therefore, the researchers relied on qualitative data to determine whether a term was an individual’s preference, a neutral response, or the most appropriate descriptor on the basis of the peer-reviewed research and common language usage. The researchers understand that parents and EHDI programs may prefer to use a different label according to regional preferences. However, it is crucial to note that the label definitions had good agreement. The participants approved the design and agreed with the comprehensiveness of the framework. The central focus of this research was to provide a solution-seeking framework and tool; therefore, decision makers are encouraged to modify terms, if desired, to better meet the needs of parents in their region.

Conclusion

This study provides revisions to the conceptual framework of parent-to-parent support developed through a scoping literature review. The conceptual framework of parent-to-parent support for parents of children who are D/HH is now grounded in the explicit and tacit knowledge of stakeholders and provides a better understanding of the role of parent-to-parent support in EHDI programs. This may have important policy development, program development, and evaluation implications and enhance evidence-based C&FCC provisions. The complementary eDelphi and scoping review methodologies provided the best approaches to this complex and important topic of parent-to-parent support.

Future Directions

The revised conceptual framework of parent-to-parent support must exist in the complexities of existing health care and environmental systems. Parent-to-parent support will interact and adapt to current EHDI programs; medical and community systems; government initiatives; cultural, kinship, and religious contexts; and other environmental factors. Partnering with the Deaf community is considered crucial.

The context of how support is provided may be as important as what support is given. Research and design of an evidence-based environmental framework of parent-to-parent support would provide insight into best-practice implementation of the current framework. The environmental context may draw attention to providing parent-to-parent support in a C&FCC philosophy and consider the legal, moral, and ethical elements of parents, organizations, stakeholders, and decision makers. Furthermore, it may help researchers understand parent-to-parent support in relation to the social determinants of health in promoting health for parents and families who are raising a child who is D/HH. Reflecting on parent-to-parent support strategies, this model is a vital research component in understanding the overall complex system of parent-to-parent support for parents of children who are D/HH.

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