A Sound Foundation Through Early Amplification

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A framework for parent-to-parent support

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Abstract

Parent-to-parent support systems can be described as a mutual process of parents with lived experiences supporting each other. For parents raising children with disabilities, including hearing loss, parent-to-parent support has an important role in their lives and encourages and supports parents in ways that are meaningful to them in their family context. Recently, Henderson, Johnson, & Moodie (2014; 2016) used a scoping review methodology and eDelphi consensus-building technique to develop and then revise the constructs and components of a framework for parent-to-parent support for parents with children who are D/deaf or hard of hearing. This article provides an overview of this framework for parent-to-parent support with the goal of educating professionals and parents about this important tenet within family-centered early intervention.

PHONAK
life is on

Introduction

Family centered early intervention (FCEI) acknowledges both the importance of provider-to-family partnerships and parent-to-parent partnerships as important principles. Attending to the affective, behavioral, and cognitive needs of parents facilitates engagement, resilience, quality parenting, family functioning, positive outcomes, and sustained participation in intervention (King, Currie, & Petersen, 2014; Gavidia-Payne, Denny, Davis, Francis, & Jackson, 2015; King & Ziviani, 2015). FCEI for families with children who are D/deaf or hard of hearing (D/HH) should include both professional-to-parent support as well as parent-to-parent support (Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013). There is a "distributed expertise" (Swallow et al., 2014, p. 70) among professionals and supporting parents that provides co-support for parents of children who are D/HH and contributes to their empowerment, knowledge, and well-being. This article focuses on the role of parent-to-parent support for parents of children who are D/HH and describes a framework for that support (Henderson, Johnson, & Moodie, 2014; 2016). It is important to note that the constructs and components described as important for parent support are equally important for professional-to-parent support underscoring the importance for professionals to be educated about the framework.

Parent-to-parent support positively impacts family well-being and enables parents to advocate for their children effectively (Joint Committee on Infant Hearing [JCIH], 2007; World Health Organization [WHO], 2016). Parent-to-parent support systems can be described as a mutual process of parents with lived experiences supporting each other. For parents raising children with disabilities, including hearing loss, parent-to-parent support encourages and supports parents in ways that are meaningful to them in their family context (Henderson et al., 2014). For parents with a child or children who are D/HH, parent-to-parent support has an important role in their lives (Poon & Zaidman-Zait, 2014; Fitzpatrick, Graham, Durieux-Smith, Angus, & Coyle, 2007; Henderson et al., 2014; 2016; Moeller et al., 2013; Schilling, Bailey, Logan, & Morris, 2015a; 2015b.

Recently, Henderson et al., (2014; 2016) used a scoping review methodology and eDelphi consensus-building technique to develop and then revise the constructs and components of a framework for parent-to-parent support for parents with children who are D/HH. The final conceptual framework is shown as Figure 1 and summarized in the following sections. Additional details on the development of the framework are found in Henderson et al., (2014) and Henderson et al., (2016).
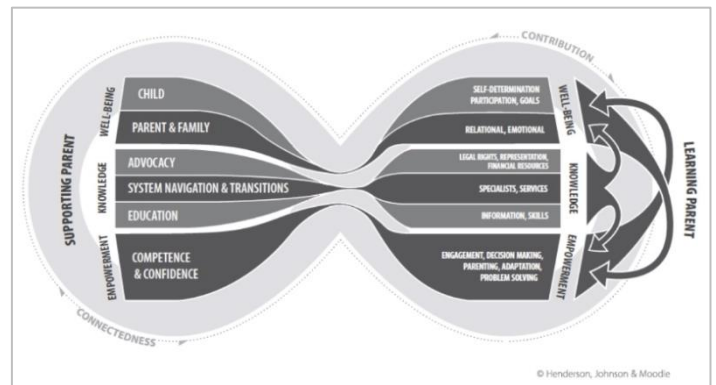

Figure 1: A framework of parent-to-parent support for parents with children who are deaf or hard of hearing. Additional details can be found in Henderson, Johnson & Moodie (2014; 2016).

There are several important starting points to understand in Figure 1 before we begin examining the constructs and components of the framework. First, the "*learning parent*" is a parent new to or inexperienced in a situation of raising a child who is D/HH. For example, the parent(s) or family might have a child recently diagnosed as D/HH or could be experiencing a transition in the child or family's life. The *"supporting parent"* has the lived experience of having a child (or children) with hearing loss. Second, there is an exchange of information between the parents. This is represented in the infographic design in the shape of a helix. Third, *"connectedness"* and *"contribution"* describe the underpinnings of the relationship. There is *connectedness* between the parents that facilitates a sense of belonging and affirms or validates a shared social identity often illustrated through anecdotal and life stories. There is the *contribution* of community relationships in their connectedness that includes, but is not limited to, D/HH role models, D/HH community, and Deaf culture, peers, social groups, and family members. This community engages with the learning parent and contributes to their overall development through the sharing of ideas, information and resources. Finally, our review of the literature revealed three overarching themes (constructs)—*well-being, knowledge, and empowerment* (Henderson et al., 2014). An important relationship exists between these three constructs and is illustrated through a series of arrows in Figure 1, namely that knowledge and well-being promote empowerment, and empowerment and knowledge increase well-being.

Child well-being

Child well-being is impacted by participation, self-determinations, and goals. Learning parents want their families to meet with other children and families who are D/HH in their community. Child well-being is facilitated by participation in leisure and extracurricular activities, daycare or school, and ventures with family and friends. Learning parents might seek assistance from supporting parents to

accrue information on participation for children who are D/HH.

Evidence indicates that learning parents might look to supporting parents to assist with access to resources or the development of their understanding of self-determination. Specifically, they want to know if there are specific actions they can take to support their children in becoming self-determined. Self-determination is a "combination of attitudes, knowledge and skills that enable individuals to make choices and engage in goal-directed, self-regulated behaviour" (Luckner & Sebald, 2013, p. 385). The importance of continued development of self-determination is that it assists an individual with awareness of personal preferences, and the ability to make effective choices and decisions. A self-determined child or family will positively impact child well-being because they are able to set goals and work toward them using strategies and supports to deal with problems (Luckner & Sebald, 2013).

Parent and family well-being
Parent-to-parent support provides relational and emotional guidance to the learning and supporting parents. Five dimensions of well-being that might be explored in this relationship include: (1) material well-being; (2) health; (3) education; (4) peer and family relationships; and (5) subjective well-being (Bradshaw, Hoelscher, & Richardson, 2007).

Advocacy knowledge
For many parents and families of children identified with hearing loss in infancy, the diagnosis is unexpected. These parents need to be provided with the resources and opportunities to support the positive development of their child to achieve whatever vision they have, regardless of disability and body function (Simeonsson, 2009). Supporting parents who have the lived experience of childhood hearing loss can be knowledgeable about legal rights, regulations, legislation, and government policies that are important for the learning parent. The supporting parent who has already learned to advocate for financial assistance, insurance, government funding, entitlements, and knows the not-for-profit or voluntary sector supplements can bring this wealth of knowledge to the relationship. In addition, it appears to be the case that supporting parents also can act as peer advocates, parental consultants, and advisors at the community, regional, and national levels until the learning parents develop strengths in these advocacy skills themselves.

System navigation and transition knowledge
Friedman Narr & Kemmery (2015) found that supporting parents spent much time mentoring learning parents on three primary themes: (1) hearing related conversations; (2) understanding and navigating early intervention programs; and (3) additional complexities of multiple disabilities. They helped learning parents understand assessment results, determine how to keep hearing aids on babies, encouraged them to attend follow-up appointments, directed them to appropriate specialists, and helped them to develop meaningful questions for specialist appointments. Supporting parents directed learning parents to early intervention programs and to programs and specialists that could assist in cases where hearing loss was not the only impairment. Two interesting outcomes of the parent-to-parent support literature that might not be commonly appreciated are that: (a) even when learning parents have reduced the amount of time they are in direct contact with supportive parents, they will increase the contact time during life transitions. For example, as the child moves from preschool into elementary school, or when they have 'aged-out' of early intervention funding programs; and (b) parents who have been trained and are acting in the role as supporting parents will seek support from other peers at times when they or their children are in transition (Henderson et al., 2014; 2016). This speaks to the importance, power, and long-lasting strength of these peer-parent relationships.

Education knowledge
Parents want to acquire information and skill. *Information* refers to being able to locate or receive accurate, well-balanced, and comprehensive information regarding technological and research advancements, and educational, communication, and assistive device options (Muñoz et al., , 2016). Learning parents might feel more comfortable asking questions of other parents of children who are D/HH. The supporting parent(s) might be able to educate parents using terms that are understood. When English is a second language, communication barriers can exist in the clinic environment. Therefore, learning parents often rely on their supporting parent who speaks the same language to educate them (Friedman et al., 2015). *Skills* refer to skill-based instruction and support, such as sign language training and education, and development of device-appropriate technological skills. These are often received as a supplement to more formal or specialized services and support.

Empowerment through confidence and competence
Self-determination is developed throughout the life span. Just as parents want their children to develop self-determination, parents continue the self-determination skill development journey themselves. Through parent-to-parent

relationships, the confidence and competence of the learning parent is facilitated through development of autonomy and relationships as they learn to adapt and adjust to life situations (King et al., 2014; King & Ziviani, 2015). Through their social connectedness with other parents, parents of children who are D/HH develop resiliency and the relationships that play a positive and proactive role in times of stress and crisis (Gavidia-Payne et al., 2015). By being engaged with other parents of children who are D/HH, parents' ability and readiness to participate in their habilitative role is strengthened. Supporting parents help to guide learning parents to the knowledge and resources needed to cultivate ideas for decision-making, problem-solving, parenting, and supporting their children's lifelong development.

Conclusion

This article describes a conceptual framework of parent-to-parent support for parents with children who are D/HH developed through a review of the literature and an international eDelphi study. The framework is grounded in the explicit and tacit knowledge of stakeholders and provides an understanding of the important and pivotal role of parent-to-parent support in FCEI programs. This framework can be used to facilitate important policy and program development and has parent-to-parent program evaluation implications.

The context of *who* gives the support, and *how* support is provided can be as important as *what* support is given (Henderson et al., 2016). Kingsnorth, Gall, Beayni, and Rigby (2011), and Shilling and colleagues (2015b) point out that although shared experience is important to successful parent-to-parent support, important organizational and processes of care must be in place. These include training, ongoing supervision, and guidance and support for the supporting parents. Our eDelphi study results concur with this (Henderson et al., 2016). Shilling and colleagues (2015a; 2015b) also point out that parent-to-parent support is person specific and it is important that we ensure we understand the characteristics of supporting parents that influence optimal outcomes as well as understand the characteristics of learning parents who desire to have and who will benefit from the parent-to-parent relationship experience.

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