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“It’s a hearing world”: Parents’ perspectives of the well-being of children who are deaf and hard of hearing

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ABSTRACT

Children with disabilities are more likely to experience challenges in their daily lives. In particular, this study explores parents’ perspectives of the social and emotional well-being of their children who are deaf and hard of hearing (DHH). Despite the importance of research in this area, few studies have addressed the views of parents of young children who are DHH in regard to social and emotional experiences. A combination of social theories guided this research – the social model of disability and the “looking glass self” theory. Qualitative semi-structured interviews were conducted with ten hearing, English-speaking parents of children who are DHH. All parents noted the significance of social and emotional development as a marker of well-being in their children’s present and future lives. Data provided evidence of how parents and children seek to adapt and cope with threats of rejection and exclusion. Inclusive practices and policies, however, have not eliminated the societal stigma and lack of understanding that children who are DHH encounter on a daily basis. The authors call for additional research that examines the perspectives of children who are DHH as a way of generating best practices across contexts to support these children.

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Social relationships are a vital, salient aspect of well-being (Arslan, 2018). These relationships exist between peers, families, communities, and help to build networks that support fellowship between people of diverse needs and backgrounds (Parcel & Bixby, 2016). The social networks and relationships we build reinforce our identity, which is noted by Leach (2015), who states that “Our identities are formed, maintained, developed and changed in relation to other people and influenced by our position within social and economic structures” (p. 35). Given the omnipresent nature of social relationships and the power they have in shaping identity, it is no surprise that the importance of “social” for the well-being of peoples, communities, and nations, is acknowledged as an

essential concept – so much so that the United Nations has named “social inclusion” a major focus for their 2030 Agenda (United Nations News Centre, 2016).

And yet, while it seems clear that social inclusion is an important indicator of well-being, acts of exclusion continue to harm or inhibit the development of social relationships by way of ostracism and stigma (Allman, 2013). The concepts of social inclusion and exclusion have been defined in various ways that “explain and at times justify why one or more groups merit access to the core or the periphery, to the benefit or expense of others” (Allman, 2013, p. 7). In particular, experiences of social exclusion are a daily reality for children with disabilities. Exclusion often stems from social stigma and children with disabilities face different forms of exclusion every day (UNICEF, 2013).

Among children with disabilities¹ who are vulnerable to social exclusion are children who are deaf and hard of hearing (Punch & Hyde, 2011). A recent study showed that children who are deaf and hard of hearing experienced higher rates of peer victimisation than children in the general population (Warner-Czyz, Loy, Pourchot, White, & Cokely, 2018). Warner-Czyz et al. (2018) attributed this finding to a few possible determining factors, such as negative parenting styles, children’s social skills, and children’s social competence (p. 292). Cross-cultural studies have also found that there is a prevalence of peer victimisation for children with disabilities (Kayama & Haight, 2018).

Research shows that social and emotional well-being is a function of social inclusion (Sette, Zava, Baumgartner, Baiocco, & Coplan, 2017). Social and emotional well-being affects quality of life. Therefore, children who are deaf and hard of hearing (DHH) – “deaf” referring to deaf individuals with little to no residual hearing and “hard of hearing” referring to deaf individuals with residual hearing (Canadian Hearing Society, 2013) – should not be overlooked when researching how children with disabilities experience social inclusion and/or exclusion. This study specifically examines parents’ perspectives of their children’s social and emotional well-being as a way of increasing our understanding and informing best practices across contexts to support these children.

Purpose

Parents play a key role in shaping their child’s socio-emotional world, especially for younger children with disabilities (Norona & Baker, 2014). Additional demands come to the surface as they learn to navigate different systems and services for their child (Ryan & Quinlan, 2018). Accordingly, the relationship between parents and their children with disabilities is a critical marker when seeking to understand how children with disabilities are faring socially and emotionally.

¹The authors recognise that disability, alongside deafness, can be interpreted in many different ways.

The purpose of this study is to address a gap in current literature that explores parents' perspectives of the social and emotional experiences of their children who are DHH as an indicator of their children's social and emotional well-being. The study further investigates how parents' perceptions of their child in turn influence their child's social and emotional health and overall quality of life.

Parents' perspectives of their children's social and emotional well-being are explored using a phenomenological approach, based on theories that focus on the powerful effects of social relationships on self-concept and well-being. This will entail exploring parents' perspectives of their child's hobbies and memorable experiences. At the root of the exploratory study is the question, how do parents of children who are DHH perceive their children's social and emotional well-being as interpreted by experiencing and observing their children's social interactions?

Frameworks

An integration of the social model of disability and Cooley's (1922) looking glass self comprised the guiding framework for this study. Taken together, the integrated features of these theories illuminate the impact of social relationships on well-being. The social model of disability asserts that society disables children who have impairments and conceives negative constructs of "disability" (Saxton, 2013), which appear to validate Cooley's (1922) theory of "the looking glass self" (p. 184). Inextricably linking social development and emotional development, Cooley (1922) states, "The thing that moves us to pride or shame is not the mere mechanical reflection of ourselves, but an imputed sentiment, the imagined effect of this reflection upon another's mind" (p. 184). If society limits the lives of people with disabilities, as Oliver and Barnes (2010) contend in their description of the social model, then it may effectively do so by way of the looking glass self (Cooley, 1922). Finally, the combination of these theories served as a framework for data analysis in that attitudes toward deafness have the power to shape and influence the everyday social interactions of children who are DHH.

Methods

This qualitative study employed semi-structured interviews as a method to ascertain parents' views of their children's lived experiences. Parents were interviewed individually and were given the privacy and time required to share their individual stories. In an attempt to respect participants' subjective experiences, interview questions were open-ended, while focused on particular themes, allowing participants some latitude in the process.

Nine out of ten participants chose to participate remotely by engaging in a phone or video interview. These two options provided parents with busy

schedules an opportunity to participate and research has shown that phone interviews can elicit in-depth narratives (Drabble, Trocki, Salcedo, Walker, & Korcha, 2016). Altogether, seven interviews were conducted over the phone, two over video call, and one in-person. Interviews lasted approximately 60 min each with two interviews lasting almost two hours. Due to the length and semi-structured form of the interviews, the methods emulate those of McCracken's (1988) "long interview", which "gives us the opportunity to step into the mind of another person, to see and experience the world as they do themselves" (p. 9).

Recruitment sites

Two Toronto-based organisations for children and families who are DHH, VOICE and Silent Voice, showed interest in this research (see Table 1). Parents from VOICE and Silent Voice were invited to participate in this study. These organisations were contacted due to their specific mandates for children who are DHH and their families. Both organisations assisted in the pre-data process by reviewing the language used on the interview schedules and consent forms. The primary researcher attended a VOICE event for parents, where a recruitment flyer was distributed and parents were encouraged to ask any questions about the research. Unlike VOICE, Silent Voice did not hold any events when recruitment took place. Nevertheless, they offered to send the recruitment flyer to members of their organisation and members of Hands & Voices, another non-profit organisation serving DHH populations.

Participants

In total, ten hearing and English-speaking parents were recruited for this study (see Table 2). Both hearing and Deaf parents were invited to participate. Silent Voice offered to provide interpretation services if a parent who did not use

Table 1. Description of collaborator organisations.

<i>Organisation:</i>	Silent Voice ¹	VOICE ²
<i>Date Established</i>	In the 1970s – became an official not-for-profit organisation in 1975	Early 1960s
<i>Founded By</i>	A Catholic priest and members of the community	Parents and remains a parent-run organisation
<i>Location Serves</i>	Downtown Toronto Children, youth, adults with hearing loss in the Greater Toronto Area, who mainly communicate using American Sign Language	Greater Toronto Area – mobile organisation 21 local chapters in over 4 provinces in Canada Primarily children who have hearing loss and communicate orally
<i>Services</i>	Delivers and develops programmes for Deaf adults and children in the American Sign Language environment	Supports the integration of children who are Deaf and Hard of Hearing in mainstream society, alongside their typically hearing peers

¹See Silent Voice (2019) for more information about this organization.

²See VOICE for Deaf and Hard of Hearing Children (2019) for more information about this organization.

Table 2. Details of study sample.

Participant	Child's gender (M/F)	Child's age	Supportive devices	Communication method
P1	M	10	Cochlear implants	speech
P2	M	4	Hearing aids	speech and basic ASL
P3	F	5	Bone-anchored hearing aid	speech and ASL
P4	F	6	Hearing aids	speech
P5	M	6	Cochlear implants	speech
P6	F	9	Hearing aids	speech
P7	F	3 ½	Cochlear implants	speech
P8	M	10 ½	Cochlear implants	speech
P9	F	6	Hearing aids	speech
P10	M	8	Hearing aids	speech and ASL

speech or English to communicate volunteered to participate in this study. However, this was not necessary, as the parents who volunteered to participate were all hearing and English-speaking parents.

Participants included nine mothers and one father. Each participating parent had at least one child who was DHH between the ages of three and 12, with only one parent having two children who are DHH. The particular age range of three-to-12 years old was chosen as these children would have had substantial social contacts with their peers (Oberle, Schonert-Reichl, & Thomson, 2010).

Data collection

Ethics approval was received from Ryerson University prior to recruitment (REB file 2017-360). Participants were reminded during the interview that if they did not wish to answer a question or continue the interview, their decision would be respected. Participants were informed that their data would be destroyed if they decided to withdraw from the study.

Data analysis

Braun and Clarke's (2006) steps for thematic analysis were adhered to in order to analyze the data in this study. NVivo 12, a qualitative analysis software, stored the data. Data was transcribed and analyzed while simultaneously being collected. Analyzing data during the data collection process helped shape and improve interview prompts with later participants.

Formal coding began by highlighting text and categorising sections of text within each transcription. Extracts of text that resembled each other in meaning were coded under the same category. In taking the advice of Braun and Clarke (2006), many sections of text were coded under as many potential themes as necessary in the beginning. Then, extracts of text were coded and recoded under different themes. Over time, as emergent themes arose, themes were revised.

Inter-rater reliability across coding was checked between the primary researcher and her co-author. After producing the initial codes, the primary

researcher, in consultation with her co-author, examined and successfully organised codes in a more logical manner by collapsing and renaming particular themes to better reflect the data contained within them. Lengthy discussions before, during, and after data collection delineated key themes to be included in a manuscript. As such, sharing data with the co-author, who also raw coded two participant transcripts, increased the credibility of this study.

Rigour

Measures were taken to strengthen the credibility and trustworthiness of this study. Member checking was used to confirm the authenticity of the data (Leech & Onwuegbuzie, 2007). Five participants were chosen at random to confirm the accuracy of their audio transcripts and provide additional information if deemed necessary. Three of the five participants responded to the request and confirmed that their audio transcripts were accurate.

In ongoing consultation with the study's co-author, the primary researcher identified codes that did not fit into any significant themes. According to Maxwell (2009), it is crucial to recognise the "pressures to ignore data that do not fit your conclusions" (p. 244). If researchers encountered discrepant data that were particularly difficult to categorise or understand, even after member checking, such data was categorised under the theme, "Outliers." In order to strengthen qualitative rigour, negative case analysis was also applied where discrepancies between prevalent and divergent data were checked (Allen, 2017).

Results

Analysis of data resulted in three major themes, filed under "Factors affecting children's social and emotional well-being." The themes were organised to emulate a range of variables that appear associated with the quality of social and emotional well-being for these children. They included: (1) external factors, which affect children and parents outside of their control; (2) child-specific factors, which are particular to children's direct experiences with language, socialising, and hobbies; and (3) parent-specific factors, which are particular to parents' involvement in their children's lives.

External factors

External factors affecting children's social and emotional well-being were noted predominantly as barriers outside of parents' control. Barriers included a lack of understanding and stigma.

All parents referred to concerns regarding societal lack of understanding on their children's disability, and the impact this had on their social and emotional well-being. In particular, lack of awareness in children's schools sometimes revolved around the school board and teachers not realising the critical need

for assisted equipment for children who are DHH. When asked to name barriers in the way of her son's success, one parent noted:

Lack of support, lack of understanding, lack of public education, too. We were making a complaint the other day and we received a comment from our school board. They said, "Well even though your son is deaf, he can see, so he should be able to do what we are asking."

Lack of understanding pervades these children's classroom experiences as well. As one parent recalled,

we had two situations at school where they never called us when the batteries died and they didn't have any ... In a classroom setting, just because she's looking at you, and her batteries are dead and the FM system is broken, doesn't mean she can hear you.

All parents were in agreement that teachers, peers, and society at large, lack understanding that could otherwise positively influence children's relationships. In addition to teachers, parents also discussed how this ignorance affected their children's relationships with peers. One parent shared, "Kids just don't understand that they have to give him time to respond. So I've seen a lot of kids ask him to play and he doesn't respond fast enough. He doesn't appropriately, so they leave him."

Reasons for a lack of understanding involved societal stigma. "We live in a world where you don't talk about your deficiencies," one parent stated. Parents spoke of societal stigma around deafness remaining a key barrier, while others spoke of society privileging those who hear "normally." In talking about her future concerns for her son, one parent said:

Life in itself is a concern. It's a hearing world. There are a lot of ignorant people. There are a lot of mean people. Not everybody is open to others that are different.

Another parent also spoke of her son encountering the societal stigma of being "deaf and dumb." She said, "... they always say, well, he speaks so he's not dumb. And it's like, deaf isn't dumb, what are you talking about?" The same parent then offered:

I think hearing loss is just so misunderstood. So many people see it as a deficit and it's something that only happens to old people and by then those old people have had a life full of sound and so they can figure it out.

In summary, each parent discussed these barriers throughout his or her interview. Whether societal lack of understanding and stigma were linked to parents' understanding of their own child or their children's self-concept, the external barriers were profound and repeatedly revisited by parents during their discussions. For this reason, parents believed that ongoing effects of social stigma and a lack of understanding combined to create a difficult climate for fostering a healthy well-being for their children.

Child-specific factors

Child-specific factors reflected those in which children themselves played an active role, such as the challenges associated with language and communication and the direct impact on social exchanges. Data showed that these challenges were closely related, where the same parents who characterised socialising as a challenge also mentioned communication as a social obstacle. As a way of coping with difficult social situations, children chose hobbies and activities which demonstrated their adaptive responses to exclusion and isolation. Findings around language, communication, and socialising are reported here.

Language and communication

More than half of parents discussed their child's challenges with speech. Parents touched on the difficulties their children experience simply learning how to speak, construct sentences, and articulate sounds. One parent noted, "L really struggles with speech sounds, he still doesn't have a firm grasp on pronouns so he refers to himself in the third person all the time still." A parent of a child fluent in sign language notes that her child's struggle with language has to do with the few meaningful conversations he can have with others. To compromise, her son will communicate using SimCom, which is a combination of English and signed English, but even this presents challenges. She shares:

He tries really hard to talk with people and make sure that they can understand what he's doing so he'll SimCom when he's talking to people. They don't understand him all the time and he's getting to that age now where the complexity of the language is increasing so much that now our family is starting to see like, okay, it's great that I know all the food signs ... But it's not a meaningful conversation.

Regarding language choices, some parents in the present study shared that there is a push from society for parents to either choose sign language or speech for their child who is DHH, however never a combination of both. As one parent noted, "You had to choose whether you were talking and you were going to get aided or whether you were going to be Deaf and doing sign. And I was like, Why can't we do both?"

While slightly over half of parents felt that their child's language presented challenges, all parents expressed that their children experience difficulties with communication in its various forms. The types of communicative challenges varied and may depend on a child's diagnosis, means of communication, and temperament. One parent expressed that his children's late diagnoses played a part in their communicative challenges. In expressing the importance of being 1–3 feet away from his children when speaking to them, he explained:

If they're not within that distance, then you can probably assume that they didn't hear everything you said. It does make it a little bit awkward ... in the sense that people ask my girls a question that they should be answering 'Yes' to, but they answer 'No,' but then people think that they're just fooling around.

Parents also shared that their children sometimes experienced difficulty speaking and fully articulating what it is they hope to express, which further inhibits productive conversation. One parent noted, “I know he’s full of ideas and opinions but he can’t get them across easily or quickly.”

Socialising

Some parents detailed how their children miss out on social opportunities as a result of not hearing their peers. One parent disclosed, “So a kid might say, M, come play with me, and she might miss out because they’re behind her and she’s listening to something else.” For these parents, it was less about whether their children can build friendships but rather, whether their children can follow a conversation and pick up on what is being said. Parents equated being able to hear as a necessary skill to enter and maintain play. Regarding the difficulty of entering play, one parent shared the following about her son:

This year he comes home and he says to me all the time, “I don’t want to be deaf.” And he’ll take his hearing aids off and he’ll give them to me ... And he says, “Mom it’s hard to socialize. I don’t know what people are saying. I can’t follow the rules of the games. They change the rules on me, and I don’t know that they’ve changed them.”

In being asked to reflect on their children’s socialising experiences, parents offered a number of events and examples. While parents shared both positive and negative experiences, negative social experiences were more prominent than positive ones. One parent described her daughter being yelled at by her friends for turning off her birthday party music:

One girl said, “Hey, why did you turn it off?” and my daughter said, “My ears are really hurting” ... And then the one kid just yelled at her, was so angry at her, “You’re turning off the music. We’re not having fun at your party.”

Parents also shared stories of their children being bullied. One parent describes how her son has been taken advantage of at school in his search for friendship:

He’s very easily taken advantage of where kids will be like, hey, give me your milk card, and buy me a milk and I’ll be your friend today. And then when the milk carton runs out, their friendship does too.

Bullying behaviour can stem from negative peer relationships, as some parents noted. Most of the parents acknowledged that bullying often took the form of their children being teased, excluded, and/or ignored.

In contrast, some parents shared stories of positive social experiences. Parents often judged the quality of their children’s peer relationships on how they interpreted their children’s emotional responses. One parent noted, “she’s very happy playing with friends ... She’s always getting invited to birthday parties.”

Three of the parents expressing positive social experiences also mentioned that their children interacted well with other children having similar needs. One parent, on the benefit of her daughter being friends with someone

similar to her, said: "I think it was really good when they were having school challenges when no one wanted to play with them that they had each other."

Likes

Physical activity. Despite their discussion of challenges, parents discussed how their children play and engage in particular hobbies. When asked what their children enjoy, all parents shared that their children liked engaging in physical activity. Parents described that physical activity was another way their children could express themselves outside of verbal communication, which significantly affects their children's enjoyment of it. On this, one parent shared: "She loves tag and very physical games ... if it was a game like chase where she doesn't have to talk, she's much more giggly and laughing." Speaking of her child's love for physical activity, another participant shared that her son "likes to do active things where he can feel his body moving and working hard."

Most parents shared that their children enjoy the physical activity of single sports, such as bike riding, swimming, ballet, and gymnastics. Parents believed that their children enjoy single sports due to the sense of accomplishment that follows teaching oneself how to independently excel at these activities. One participant recalled her son feeling very happy on account of single sports: "When we went skiing, it was difficult for him at some points but at the end of the day, he was able to go down [the hill] and he was really happy about it."

Overall, parents conceded that physical activity played an important role in their children's social and emotional well-being. In particular, physical activity appeared to provide a therapeutic space, often mitigating verbal communication challenges, for children to express themselves and succeed. On the effect of sports on her child's life, one parent shared:

... if he didn't have sports and that outlet of release to go off and just like kick a ball around for an hour and half and take his stress out on the ball, I don't know that he would be as happy as he is. He's happy because he has different releases that he can do.

In summary, key factors associated with children's social and emotional well-being included children's activity preferences and social skills. Children's challenges with language, communication, and socialising also played a significant role in shaping their activity preferences.

Parent-specific factors

Parents are integral in supporting and promoting children's social and emotional well-being. Significant themes included parents' involvement in their children's lives and ongoing concerns for their present and future well-being.

Generally, parents conveyed high levels of involvement in their children's lives due to their desire to best support and understand their children and their

deafness. The involvement of parents tended to fluctuate from low to high, depending on the need and context. For the majority of parents, high levels of involvement were shown in the decisions made regarding their children's extra-curricular activities. One parent noted, "She's not an outgoing kid, so we've kind of stuck her in things we know she would like." Another parent shared, "We keep encouraging him to do tennis, swimming, and these sorts of activities that can help him work on his gross motor and a general awareness of his body." For many parents, choosing their children's extra-curricular activities meant choosing what they felt would benefit their children the most. In their own way, each parent described being highly involved in aspects of their child's life and less involved in other areas.

The level of parental involvement was related to specific concerns for their children's social and emotional well-being. As one parent stated, "our main concern is the social and emotional, and her making friends, and just interacting with kids." One parent remembered questions she asked herself once learning about her child's diagnosis:

Oh my god, is she going to be bullied? Is she going to be picked on? ... Is she ever going to have friends?

The majority of parents, in being asked to look ahead, worried more about their child's social and emotional success than their child's academic success. To this exact point, one parent shared:

I don't care if he's at the bottom academically ... I just want him to feel like he fits in with his peer group and that he belongs with his peer group and that he's happy with them ... That's my goal for him, for him to have good friends.

Concerns about children's social and emotional well-being were made easier for parents to handle with the help of resources. Valuable resources included contact with community organisations and other parents of children who are DHH as well as children's supportive devices. Missing resources included education for parents around deafness.

Parents noted that many resources came at an extra cost. Costs often prohibited access for some families who cannot afford privately obtained supports. One parent wondered: "What do the families do that are between jobs? Or on welfare? ... that makes me sad that some kids who are in exactly in E's situation aren't able to get what they need to develop."

With many parents, there was a sense of being "lucky" to be able to afford the extra costs associated with extra-curriculars and therapists. One parent said: "We're lucky that my husband has a really good job so we can afford for me to stay home with [our son]." For the majority of parents, however, seeking inexpensive and useful resources was difficult, which confirmed a societal lack of understanding around deafness.

Discussion

The aim of the study was to explore parents' perspectives of the social and emotional well-being of their children who are DHH as identified by these parents' experiences and observations of their children. Salient themes in the data revealed concerns regarding the relentless forms of societal stigma which continue to plague the social and emotional well-being of these children. Parents described their frustrations at not being able to break through these incessant barriers despite their commitment and advocacy efforts. According to the parents, these barriers inhibited their children from living full and inclusive lives in their communities. Of the parents who voiced their children's social and emotional development as a major concern, nine out of the ten also shared that their children experienced instances of bullying.

In spite of these realities, parents cited numerous instances where their children thrived. Data showed that all children enjoyed physical activity, particularly single sports. Single sports allowed their children to enjoy and engage without necessarily needing to communicate with anyone. Additionally, single sports provided a space for children to thrive without necessarily having to navigate the pressures of language, communication, and socialising. This emergent finding contrasted data found in another study with parents of children with disabilities in rural areas, which found that 73% of parents reported their children not engaging in enough physical activity (Wakely, Langham, Johnston, & Rae, 2018, p. 34). Researchers mainly attributed this to the cost of sports equipment and travelling long distances from rural areas to sports' gatherings (Wakely et al., 2018).

However, excelling at a single sport has not alleviated parents' concerns about their children's social and emotional well-being. Some parents shared that their children's negative social experiences predispose them to avoiding situations which can elicit rejection or bullying. For this reason, these children are often inhibited from initiating friendships and building their self-confidence. Thus, a cycle of societal stigma, lack of understanding, exclusion, and loneliness for parents and their children who are DHH ensues. These data show that parents appear highly involved in their children's lives but a level of isolation persists for these children as a result of the stigma. And yet, recent research has concluded that deaf children, as well as hearing children, can benefit from mutual play or, "communities of practice" (Kristoffersen & Simonsen, 2016).

Alongside parents' concern for their children's social lives come particular tensions around communicative language choices. The potential effects of these decisions on children's identities should be addressed. Research shows that the debate between choosing sign language and speech, as well as the tensions inherent in choosing a combination of both, lives on, where parents are put in an "either-or" dilemma when evaluating their children's language options (Archbold & Mayer, 2012; Humphries et al., 2012; Hutchison, 2007). Deaf scholars assert that

colonialism manifests itself in Deaf communities through “Oralism,” which is the adoption of speech-only communication methods for individuals who are DHH and is viewed by Deaf scholars as an abandonment of all things “Deaf” (Ladd & Lane, 2013, p. 569). Historically, teachers and parents who wanted their children to speak supported the premise behind Oralism – that is, teaching children who are DHH oral-only communication methods (Hutchison, 2007, p. 495).

The prevalence of oral-only communicative methods in dominant society has led Deaf scholars to further advocate for the sign language rights of children who are DHH so that children are educated about alternatives to oral language (Humphries et al., 2013; Paul & Snoddon, 2017). Given the tension surrounding these issues, it is important to consider their impact on parents and, of course, on the social and emotional well-being of children who are DHH. That is, on top of having to choose between oral-only communicative methods and sign language methods for their children, parents must also navigate the conflict between the two sides while also keeping in mind that there is societal pressure on their children who are DHH to “talk” and communicate like the rest of the “hearing” world. Amidst these tensions around communication, language, and societal pressures are the children themselves, who are often forgotten in discussions about their well-being and future.

In summary, there are several factors associated with the social and emotional well-being of children who are DHH. It is important to decipher which one of these issues require the most attention so that the quality of life for these children and families are improved. Societal stigma, peer rejection, and the support of parental advocacy as well as the child’s own abilities to assert change must be viewed as a multifaceted and systemic enterprise. The findings from this study corroborate the theories that guided this research and support the link between the social model of disability and Cooley’s (1922) “looking glass” theory. Together, they assert that parents recognise societal stigma around their children who are DHH in ways that, in turn, reflect their children’s social and emotional well-being.

Rawls and Duck (2017) use Cooley’s looking glass to inform their understanding of a “Fractured Reflection” – where individuals apply stereotypes and assumptions to individuals that they cannot recognise in themselves (p. 38), as is sometimes the case when an able-bodied person encounters a disabled person. This fractured perspective results in a broken mirror of sorts, which has consequences for the misrepresented self, put forward by the other participant (s) within the social interaction. This extension of Cooley’s work is useful here when considering how parents navigate and learn of their children’s relationships with peers and teachers (even sometimes dealing with peers’ and teachers’ fractured reflections of their children) and thus, how these interactions shape their children’s social and emotional well-being as well as their own emotional health.

Under Article 24 of the UN Convention on the Rights of Persons with Disabilities (CRPD), it writes that “state parties [countries] are specifically charged with

the obligation to ensure access to inclusive general education with non-disabled peers” (Inclusive Education Canada, 2017). Given the children’s social and emotional challenges in this study, as observed by the parents, it can be argued that children who are DHH are not being granted meaningful access to inclusive education with their non-disabled peers and teachers – access to which they have a right.

Lacking meaningful access to inclusive education in schools is reflective of the larger issue of societal lack of understanding. In order to combat the societal lack of understanding, which stands in relation to stigma, it is essential that children who are DHH are invited to share their perspectives on their own social and emotional experiences. Speaking to parents, while valuable, is only one part of a complex story. Next steps should endeavour to centre the stories of children who are DHH so that the complexity of their social and emotional lives is further highlighted and supportive practices can be identified.

Limitations

Due to the qualitative nature of this study, findings are not generalisable. Parents, as participants, do not represent the views of children. For this reason, children’s interpretations of their experiences cannot be fully captured. Furthermore, only hearing, English-speaking parents participated in this study, excluding the perspectives of parents are DHH and who do not speak English.

Strengths

This study contributes to existing literature that cites the prevalence of external barriers and the effects on children’s social and emotional well-being. In particular, this research was conducted with parents of children, not adolescents, which contributes to the lack of early childhood research in this area. Participants in this data also expressed agreement on major themes, despite differing in experiences of parenting and deafness as their children varied in severity of deafness, use of supportive devices, and age. Regarding the study’s methods, the choice of individual, semi-structured interviews allowed for greater participant control, more nuance, and rich data (Adams, 2010).

Conclusion

Social and emotional well-being of children was a priority for all the parents in this study. Parents’ sentiments provide further evidence of the importance of the social context for ensuring a successful life despite the challenges of living in a society that stigmatises disability. The combined frameworks of Cooley (1922) and the social model of disability are validated here as parents described the impact of their children’s social interactions on their families. If children with

disabilities continue to receive messages that reinforce difference and exclusion, they are less likely to build self-confidence and strong identities. Therefore, these discursive constructions of deafness set up the possibility for its marginalisation in society as an “excludable type” (Hindhede, 2012, p. 180).

Because these issues are complex and intertwined, policy makers, educators, and society at large, must consider a collaborative approach to combatting the way in which we view these children. As noted, we need to attenuate gaps in the literature that exclude the voices of children with disabilities. Future research must include children of various ages, backgrounds and hearing abilities in order to delineate next steps that can combat a complex multitude of barriers that stand in the way of healthy social and emotional well-being for these children.

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No potential conflict of interest was reported by the authors.

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