

## EMPIRICAL MANUSCRIPT

# Children With Mild Bilateral and Unilateral Hearing Loss: Parents' Reflections on Experiences and Outcomes

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## Abstract

Children with mild bilateral and unilateral hearing loss are now commonly identified early through newborn hearing screening initiatives. There remains considerable uncertainty about how to support parents and about which services to provide for children with mild bilateral and unilateral hearing loss. The goal of this study was to learn about parents' experiences and understand, from their perspectives, the impact of hearing loss in the mild range on the child's functioning. Parents of 20 children in Ontario, Canada, participated in the study. The median age of identification of hearing loss was 4.6 months (interquartile range: 3.6, 10.8). Parents appreciated learning early about hearing loss, but their experiences with the early process were mixed. Parents felt that professionals minimized the importance of milder hearing loss. There was substantial uncertainty about the need for hearing aids and the findings suggest that parents need specific guidance. Parents expressed concerns about the potential impact of hearing loss on their child's development, particularly at later ages.

Milder forms of childhood hearing loss are now being identified early due to population-based hearing screening, an intervention now widely implemented to alleviate language delays associated with early hearing loss. Hearing loss affects 3 to 4 per 1,000 children when all degrees of severity are taken into account, including mild bilateral and unilateral losses (Prieve & Stevens, 2000; Watkin & Baldwin, 2011). The consequences of permanent childhood hearing loss of moderate degree or greater have been well documented and typically include important delays in communication, academic, and social development (Ching et al., 2013; Kennedy et al., 2006; Moeller, Tomblin, Yoshinaga-Itano, Connor, & Jerger, 2007; Wake, Poulakis, Hughes, Carey-Sargeant, & Rickards, 2005). However, the effects of mild bilateral and unilateral hearing loss are much less understood. Consequently, neonatal screening programs have adopted different definitions of the target hearing loss with some regions

specifically screening for hearing loss of moderate degree and greater (e.g., Australia, United Kingdom) while others also include milder degrees of loss (Hyde, 2005). In programs where milder forms of hearing loss are included in the testing protocols, the benefits of such initiatives remain largely unknown.

Historically, in the absence of newborn hearing screening, children with mild forms of hearing loss were not identified on average until age 4–5 years (Fitzpatrick, Durieux-Smith, & Whittingham, 2010; Fitzpatrick, Whittingham, & Durieux-Smith, 2014; Tharpe, 2008). Therefore, most of what is known about the effects of mild bilateral and unilateral hearing loss is based on studies of late-identified children. A series of papers in the 1980s to 1990s, now summarized in recent reviews, documented some of the difficulties experienced by children. These studies indicated that up to one-third of affected children failed at least one school grade (Lieu, 2004; Tharpe, 2008; Wake & Poulakis, 2004).

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More recently, research showed that a group of 6- to 12-year-old children with unilateral hearing loss achieved significantly poorer speech and language outcomes than their siblings with normal hearing and were 4.4 times more likely to require special assistance in school (Lieu, Tye-Murray, Karzon, & Piccirillo, 2010). However, the majority of these children were late identified through preschool or school screening at age 4.7 years. In a subsequent longitudinal study, while children improved their oral language skills, academic difficulties and behavioral problems persisted (Lieu, Tye-Murray, & Fu, 2012). When mild hearing loss is targeted, newborn hearing screening can reduce the age of identification for these children from average age of 5 to 8 years (Fitzpatrick et al., 2014). Essentially, this represents a “new” population of children whose parents now require support from the time that hearing loss is identified, which now often occurs in infancy.

There is evidence that parents are often overwhelmed when first learning about their child’s hearing loss (Kurtzer-White & Luterman, 2003). These feelings can be magnified when parents are presented with technical information as well as choices about hearing technology and intervention (Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008). Concerns about communication development and educational achievements along with the demands for increased audiological and medical care seem to contribute to parent stress (Lederberg & Golbach, 2002). However, little is known specifically about how parents of children with milder losses are affected when learning about hearing loss and by the need for decision making in the early years.

Of fundamental importance for these parents is that due to the limited information about the consequences of early identified mild bilateral or unilateral hearing loss, there appears to be considerable variation in audiological and educational practices. Intervention seems to range from watchful waiting to the fitting of amplification and communication development support. In particular, that there is considerable uncertainty about the benefits of hearing aids and when to introduce them. In a Canadian study of 337 children identified with mild bilateral and unilateral loss between 1990 and 2010, 87.2% of children eventually received recommendations for amplification. However, there was considerable delay to the fitting of hearing aids for more than 50% of children and the reasons delaying decision making are largely unknown (Fitzpatrick et al., 2014). Late age of identification was associated with amplification, as older children were more likely to receive recommendations for amplification than early identified children. Furthermore, when fitted, amplification use is problematic with studies reporting consistent use ranging from less than 50% to 70% (Davis, Reeve, Hind, & Bamford, 2001; Fitzpatrick et al., 2010, 2014; Reeve, 2005). Other researchers have also highlighted the lack of information and the difficulties related to amplification decisions for these children (McKay, Gravel, & Tharpe, 2008; Porter & Bess, 2011; Tharpe, 2008). Recently, in an investigation of hearing aid use in young children, Walker et al. (2013) showed that children with mild bilateral/unilateral loss were among the most inconsistent users of amplification. Previously, Moeller, Hoover, Peterson, and Stelmachowicz (2009) also called attention to the difficulties parents of children with mild to moderately severe hearing loss experience in establishing consistent hearing aid use in the early stages of device fitting. However, there is emerging evidence from early identified children that hearing aid use is associated with better speech-language results, particularly for children with mild hearing loss (Tomblin, Oleson, Ambrose, Walker, & Moeller, 2014).

## Parent Perspectives

Several researchers have highlighted the importance of including parents’ perspectives in understanding and defining appropriate care for children with hearing loss (e.g., Fitzpatrick et al., 2008; Tattersall & Young, 2006; Young & Tattersall, 2007). In particular, since moving from a parent-initiated to a system-driven process of screening and early intervention of hearing loss, parents’ views have been valued in informing clinical and educational practices. For example, Tattersall and Young (2006) identified that professionals’ communication and manner were the most important predictors of parents’ early experiences with their child’s hearing loss. One key theme emerging from studies of parents’ views since newborn screening is that they increasingly define expectations for their child in relation to auditory, speech, and language development for children with normal hearing (Fitzpatrick, Graham, Durieux-Smith, Angus, & Coyle, 2007; Young and Tattersall, 2007). A second important theme from these and other studies (e.g., Calderon & Greenberg, 1999; Most & Zaidman-Zait, 2001) is the need to extend services beyond child interventions to include family support. However, most studies have included primarily parents of children with moderate to profound hearing loss. To our knowledge, there has been no research focused specifically on the perspectives and experiences of children with milder forms of hearing loss.

## Context and Study Objectives

In 2002, a province-wide universal newborn hearing screening program was implemented in Ontario, Canada’s most populous province of 11 million people. Unlike some programs, that screen for hearing loss of 40 dB or greater, the program specifically includes mild bilateral and unilateral hearing loss in the target disorder on the basis that these children are at risk for progressive hearing loss (Hyde, 2005). The Joint Committee on Infant Hearing (2007) also stated the importance of identifying all severity of hearing loss and noted that even mild hearing loss is associated with developmental consequences. In addition to screening and identification, a core characteristic of the provincial program is the inclusion of services focused on parent support, early hearing, and communication development (Hyde, Friedberg, Price, & Weber, 2004).

In the context of this publicly funded newborn screening program, a multicenter study was undertaken to examine outcomes in children with mild bilateral and unilateral hearing loss and to gain a greater understanding of the benefits and experiences of early detection for parents of these children (Fitzpatrick, Durieux-Smith, Gaboury, Coyle, & Whittingham, 2015). One component of the larger study involved qualitative interviews with families to gain an enhanced understanding of the benefits and experiences of early identification for parents of children with milder losses. Specifically, the objectives of the qualitative inquiry were to gain insights into: (a) parents’ experiences in learning about hearing loss, (b) parents’ perspectives of the impact of milder hearing loss on their child’s development, (c) parents’ needs in the early stages of learning about and managing their child’s hearing loss, and (d) the important elements of a service delivery model for families following identification of milder hearing loss. Through the narratives of families of young children with hearing loss, this paper reports the findings for the first two objectives specifically related to parents’ experiences and their perceptions of the impact of mild bilateral and unilateral hearing loss in the preschool years.

## Methods

### Design

This inquiry employed a qualitative research approach to examine parents' experiences with the identification of hearing loss as well as their views on their children's functioning. Qualitative techniques were adopted to capture data that were meaningful to parents to complement those collected through traditional quantitative assessment techniques. There is wide recognition of the contributions of qualitative methods to explore questions less amenable to quantitative methods such as the examination of aspects of development beyond traditional outcomes (e.g., speech and language results) and to the understandings of findings from quantitative studies (Moffatt, White, Mackintosh & Howel, 2006; Pope & Mays, 1995, 2000).

### Participants

The sample frame for this inquiry was drawn from the first 38 families who were enrolled from 2009 to 2012 in the longitudinal project investigating communication outcomes in early identified children with mild bilateral or unilateral hearing loss (Fitzpatrick et al., 2015). These families were recruited through six Ontario programs in three regions, Ottawa, Toronto, and Southern Ontario. Consistent with the inclusion criteria for the larger study, parents of children with the following characteristics were eligible to participate: (a) chronological age less than 3 years at study enrollment, (b) permanent mild bilateral or unilateral hearing loss, (c) congenital or early onset hearing loss, (d) English as one of the languages spoken at home. Both parents who were hearing or deaf were eligible to participate, however, at the time of the interviews, no parents with hearing loss had enrolled in the study. Children with hearing loss and additional complex disabilities, that prevented them from developing oral communication, were excluded from the larger study due to the requirement to complete multiple spoken language assessments.

For the interviews, the research project coordinator contacted the families who had indicated, via the consent form, their willingness to participate in an interview. Attention was given to including parents of children with different hearing characteristics (e.g., bilateral, unilateral), identified at different ages and from different regions represented in the larger study to allow a diverse range of perspectives and experiences to the extent possible within the larger study inclusion criteria. To ensure a varied sample, we monitored the enrollment to ensure the inclusion of children with a range of characteristics. In accordance with previous patient-interview studies, it was anticipated that 15–20 participants would constitute a sufficient number to reach data saturation for this study and to permit the emergence of common themes from different perspectives (Kuzel, 1992).

However, sampling in qualitative inquiry is generally flexible and the option was available to invite more parents as the study progressed. Ethical approval for the research was obtained from the University of Ottawa and from all institutions involved and written informed consent was obtained from the participants prior to the initiation of data collection.

### Description of participants

Parents of 20 children (19 mothers alone, 1 mother and father together) participated in the interviews. All families had one child with hearing loss with the exception of one family who

had two other children with moderate hearing loss. Child and family characteristics are shown in Table 1. Participants were diagnosed in the Ottawa, Toronto, and Southern Ontario regions in the province of Ontario. Consistent with the distribution of hearing loss in the larger study, 9 children had bilateral and 11 unilateral loss. A total of 18 children underwent neonatal screening but one passed screening and later returned to audiology due to parental concern. This was an early identified group with a median age of confirmation of hearing loss of 4.6 months (interquartile range [IQR]: 3.6, 10.8). In the unilateral group, 7 of 11 had 40 dB hearing loss or greater loss in the ear with a hearing loss. In the bilateral group, three of nine had greater than 40 dB hearing loss in the worse ear. Seventeen (85%) had received amplification at a median age of 15.2 months (IQR: 5.5, 25.9) and the remaining three were being monitored. Eight children were fitted before age 12 months. Of the seven children with known etiology, three had a family history of hearing loss; one of these had two siblings with moderate hearing loss. Sixteen (80%) of the parents reported that their children were enrolled in a regular early intervention program ranging from weekly to monthly

**Table 1.** Characteristic of children with mild bilateral and unilateral hearing loss

Characteristics	Participants (n = 20)
Sex, n (%)	
Male	9 (45)
Route to confirmation of hearing loss, n (%)	
Screened	18 (90)
Not screened	2 (10)
Age confirmation hearing loss (months), median (IQR)	4.6 (3.6,10.8)
Onset of hearing loss, n (%)	
Congenital	16 (80)
Early onset	2 (10)
Late onset	2 (10)
Hearing loss, n (%)	
Unilateral	11 (55)
Bilateral	9 (45)
Type of hearing loss, n (%)	
Sensorineural	14 (70)
Permanent conductive	4 (20)
Mixed	2 (10)
Amplification, n (%)	
Hearing aids	17 (85)
Monitored– no amplification	3 (15)
Age of amplification (months), median (IQR)	15.2 (5.5, 25.9)
Etiology, n (%)	
Known <sup>a</sup>	7 (35)
Unknown	13 (65)
Age of interview (months), mean (SD)	28.6 (9.3)
Maternal education (years), mean (SD)	17.2 (2.4)
High school, n (%)	3 (15)
College/university, n (%)	17 (85)
Family income, n (%)	
<80,000\$ <sup>b</sup>	5 (25)
>80,000\$	15 (75)

Note. IQR = interquartile range.

<sup>a</sup>Three children had known family history; one had two siblings with moderate hearing loss, one had a father and one a maternal aunt with hearing loss.

<sup>b</sup>Median family income reported by Statistics Canada in 2012 for the three metropolitan regions where children were recruited ranged from 71,210\$ to 94,230\$ (Canadian dollars).

services. Children had a mean age of 28.6 months (SD: 9.3) when interviews were conducted, therefore the majority of parents had less than 2 years experience with hearing loss. This was a well-educated group of parents with an average of 17.2 years (SD: 2.4; range 13–23) of education and 17 mothers having completed post-secondary studies.

#### Ontario context

In the Ontario program, children who do not pass screening are referred from the screening program for a diagnostic audiology assessment in a designated pediatric audiology center. When a permanent hearing loss is confirmed, children are also seen by an otolaryngologist for a medical evaluation, to confirm permanent hearing loss and to receive medical clearance for hearing technology, if applicable. The audiologist meets with the family regarding hearing technology options. Families are also referred to a family support worker, a professional who guides the family (Brown & Mackenzie, 2005) with respect to intervention service options and other resources the family can access (e.g., financial support for hearing aids, community support, other developmental specialists). Parents make a choice about using hearing technology and choose intervention from several available approaches ranging from a focus on oral communication (e.g., auditory-verbal therapy) to those with an emphasis on visual learning (e.g., American Sign Language) (Brown & Mackenzie, 2005; Hyde et al., 2004). Children continue to be followed audiotically at 3-month intervals or more frequently if needed, during the first few years until audiological information and hearing technology use are established. Early intervention is available in a variety of settings such as hospital audiology clinics, community speech-language centers, and home-visiting programs and may be offered by various specialists, including auditory-verbal therapists, speech-language pathologists, and teachers of the deaf and hard of hearing. Frequency of intervention, often weekly for moderate to profound hearing loss, is determined with the child's intervention program. These services are publicly funded for all families. At school age, intervention generally becomes the responsibility of the public school system.

#### Procedures: Interviews and Data Analysis

A total of 20 individual semistructured interviews were conducted with parents. This format was selected so that parents could comfortably describe their experiences related to the early stages of learning about their child's hearing loss and also because families were located in various regions. The meetings were conducted in the parents' home when possible or by telephone or Skype when distances prohibited travel. Twelve interviews were conducted in-person and eight via telephone or Skype. One researcher with 25 years experience in pediatric audiology and family-centered intervention programs conducted all interviews.

An interview guide (Appendix) was developed to structure the conversation with parents and ensure that the important topics of interest were covered. The interview began with open-ended questions to encourage participants to share their experiences about the process of learning about their child's hearing loss. Questions also probed parents' views of their children's functioning and any concerns. Consistent with qualitative research practices, questions were added in response to parents' comments to engage in a conversation with them. Interviews were audio-recorded with participants' consent and transcribed verbatim to facilitate detailed analysis. Brief field notes were

written after the interviews to summarize overall impressions and to highlight any notable areas of discussion.

Characteristics were collected for all families through questionnaires as part of the larger longitudinal study at enrollment and at 6-month intervals. Information related to hearing loss including age of identification, intervention, type, and laterality of hearing loss were collected from the clinical chart for the Ottawa area families and from the child's clinical audiologist for other participants. The parent questionnaires were used to validate this information and provided additional details concerning parent education, income, and the child's intervention program. A descriptive analysis of the characteristics of the subset of participants in the qualitative inquiry was compiled from data collected in an SPSS database (version 22) for the entire longitudinal study group.

#### Data analysis

Consistent with qualitative research techniques, data collection and data transcription proceeded concurrently such that the preliminary analysis could guide future data collection. In addition to reading the written transcripts, the researcher who completed the interviews listened to the recordings. The transcripts were entered into qualitative research software, N-Vivo (version 10.1.2) for detailed coding. Two research assistants, one psychology student and one doctoral student in rehabilitation sciences, transcribed the recordings verbatim and the lead researcher verified the accuracy by listening to the recordings and reviewing transcripts. The coding process involved a constant comparative method based on open, axial, and selective coding methods (Corbin & Strauss, 2008). Two researchers first performed open coding of the transcripts, which involves breaking down data into discrete segments to specifically label comments as concepts or categories. One researcher was the lead investigator and the other was a doctoral student in rehabilitation sciences with a background in linguistics and research experience in hearing loss. Codes were then compared to ensure consistency and to discuss any differences in coding. A third researcher, a student who was trained as an audiologist and speech-language pathologist, read the transcripts and confirmed or added codes. Any addition of new codes was discussed among the three researchers. Subsequently, during axial coding, the two researchers who did the initial coding, examined the codes and discussed them with a third researcher to form links and connections or categories of codes. During the final selective coding process, categories were integrated to condense the findings into major themes. In addition, the interviewer's notes and reflections postinterview were used in finalizing key concepts. Interviews were continued until data saturation was reached, that is no new themes emerged during the analysis.

#### Results

The overall aim of the interviews was to better understand parents' experiences with the process of learning about their child's hearing loss, as well as their perceptions of their child's functioning. No decision was made a priori to combine information related to children with mild bilateral and unilateral hearing loss. During data analysis, few differences emerged specific to unilaterality of hearing loss, therefore, we did not separate the results on this basis. Six key themes were assembled from the interview data: unexpected hearing loss, screening is positive, experiences with early identification, minimizing important of hearing loss, uncertainty about amplification, and concerns about development. Each theme is elaborated below supported

by examples of parents' comments. The letter-number after the parent quotes identifies the interview.

### Unexpected Hearing Loss

Several parents shared their surprise about learning of their child's hearing loss. Despite a referral to diagnostic audiology from screening tests, 15 of the 20 parents indicated they generally had no concerns based on their observations at home and saw the audiology appointment as a routine event. As illustrated in the comment below, some parents even described a "false sense of reassurance" based on comments of professionals at the time of screening.

I mean at that point, we thought he had normal hearing, we didn't have any concerns, he was reacting to sounds, he would turn, he would look... (p. 15)

And we did the ABR, and at that time, I had gone by myself because at that time I really didn't expect to find that she had a permanent hearing loss, I just figured it was the fluid in the ear, the amniotic fluid that was in her ear, and [it] would be gone. (p. 17)

And again we were reassured that it was probably because there was still fluid in the ears, given that she was born from an infection. You know, we had good test results on the MRI and everything else. So this one for me, when it happened in June, it was a huge shock, and I had no exposure to hearing loss with my family or with friends. (p. 10)

### Screening Is Positive

Parents' appreciation of early identification of their child's hearing loss emerged as a common discussion point. Almost all parents saw screening as positive and a service they appreciated because it permitted them to be aware of their child's hearing difficulty from the early months of life. Many commented that, without screening, they would never have noticed a hearing loss because the effects on the child's development were not at all obvious.

I'm thankful for infant screening, I know that there are some provinces in Canada that don't have screening...I know for [Child's] type of hearing loss, it wouldn't be picked up until she was two or three years old. (p. 13)

... he's almost two now and we almost don't notice his hearing loss at all and we probably wouldn't have noticed it until he's in school. But just the fact that we've been given all these tools and all these resources, we're really really happy about that and we think it's an excellent program.... the earlier you find out with all the resources we feel that it's definitely an advantage. (p. 4)

### Experiences With Early Diagnostic Process

While some parents had positive experiences and talked about a smooth process from screening to identification, others spent considerable time reflecting on difficult aspects related to the process. Frequently, these were not specifically attributed to any aspect of service quality but rather the challenges of confirming a mild loss. Considerable discussion centered on the uncertainty around the audiological results, including the challenges of testing a young child and the number of visits required to reach a conclusion about the presence, type, and severity of hearing loss.

So, she has a unilateral loss. So, first, they were thinking, maybe it's something with her ears, so they just basically said, we should go to an ENT. So we got in line for that and then they just wanted to monitor it and see whether it was conductive or not, they ended up doing four ABRs which were the same. (p. 19)

...for those first two months, we were under the impression that his left ear is failing the test, but he [could] still hear from the right ear. That's what we thought. (p. 7)

Other parents described a number of service-related events that created anxiety or concern in working through the early process. These families came from six different regions throughout the province and services seemed to vary considerably. While many parents had positive encounters, several others described breakdowns in the system.

What I found most disconcerting is that there wasn't a place, where we could go, and [hear], ok, this is what's going to happen next, you're going to have tests every so often, these are the services that are available to you, that didn't happen. It was me running around, calling everybody, getting online... and I found that in Ontario that's where the breakdown happens. (p. 17)

A number of parents also described a high level of satisfaction with the flow and quality of services. Of note, was parents' high level of satisfaction with family support workers, a professional who meets with parents when hearing loss is first diagnosed, to provide initial support and information about intervention options and resources.

Well, everything has been great, we met with a family support worker and she just sort of gave us an overview of what was available. At the time, we didn't take a lot of it in because he was [identified with] a mild loss and it was an overview and we weren't really concerned at the time. (p. 8)

They actually told me everything, all the supports that were in the system, and [about] the hearing, they talked about the hearing aids and the different options. (p. 12)

We feel very fortunate that we have a good program here, and in addition to that, just having professionals taking it...seriously, a hearing loss is a hearing loss, whether it's in one ear or both ears. (p. 19)

### Minimizing Importance of Hearing Loss

One of the key discussions about the early process was that some professionals minimized the importance of the hearing loss. Parents even described some clinicians' attitudes as "dismissive." A common perception was that their child was a lower priority because of the milder nature especially when it was a unilateral hearing loss. Some parents commented that technical expertise was of high quality but that emotional support was missing. The following examples illustrate parents' reflections on their experiences.

She [the audiologist] didn't think it was a big deal, like it's one way when you go to the doctor and they are reassuring and saying everything is fine. But it wasn't really in that way either, it was just like, oh well, he has one good ear. (p. 11)

So unfortunately the same thing happened at [Hospital], they said adequate hearing for speech and sent us away. And it's hard because I know...they have a huge caseload, and yes the hearing losses are more severe, but it's my kid, but to them, it's just one ear.... (p. 19)

The prevention is not there, it's not that she wasn't a priority, it's not that everybody wasn't being helpful. ...it's just that, unless her speech and language was delayed, she wasn't going to be put into this program, and my feeling was why are we going to wait until her speech and language is delayed, let's intervene now. (p. 17)

I think that the other part of the equation is again that emotional, psychological support for parents so that they know that there are resources out there, that there are groups of people... who have had the same experience, who can provide the stability... (p. 9)

## Uncertainty About Amplification

### Professional uncertainty

There was considerable uncertainty about the need for and benefits of hearing aids. For some parents, this was particularly amplified when professionals such as the otologist and audiologist expressed different views about the potential benefits of hearing aids. Many comments, as exemplified below, referred to indecision created by professionals' uncertainty while others seemed to be based on the parents' own observations. For some parents, the hesitation or lack of conviction on the part of professionals seemed to lead them to conclude that hearing aids were optional rather than recommended.

She (the audiologist) said, if we like, we can go ahead and get the hearing aids, he's doing fine, but just to be sure, go ahead and get hearing aids. But, we started his daycare and that was already a big transition for him, so we didn't want to introduce the hearing aids right then. (p. 12)

Because she was doing so well, it's like, do you force a child to do this? She was obviously not going to be a willing participant, you know, you didn't know what benefit she was actually going to get. (p. 16)

### Parents' need for support for using amplification

Closely related to the parents' apprehension about amplification, was the need for support in using it when they decided to go ahead with audiological recommendations. Some parents described the difficulty of ensuring hearing aid use with a young child. Parents' comments suggested that this was likely intensified when they did not see immediate results or differences in functioning with amplification, leading them to "forget" to use amplification as one parent noted.

[She] wears it all the time now, at the beginning to be honest, it was me forgetting, because as the parent you have to remember. (p. 2)

...just going to the clinic and being reminded that oh, she can't do this, she can't do that, through the testing, but when you're home with her, ...I feel like she is totally normal, I don't feel like she has a hearing loss. Because sometimes when she doesn't have her hearing aids on, I don't feel like she doesn't hear it, I know that she needs it on because she does not detect everything and I know the results, that she does need this, but then without it I don't see much difference in her not having it on. (p. 14)

### Parents' realization of amplification benefits

A number of parents commented that with time, they learned to appreciate the benefits of amplification, either because they observed behavioral differences or because they better understood the impact of hearing loss.

She was 19 months [when she received hearing aids]... probably about [age] 3; three months ago we realized how much she notices a difference. Well she kept pulling it out and handing it to my husband ... and then we realized the battery didn't work, ... and that's why she kept pulling it out. And so now in the mornings when we're getting her ready, if we don't put it in... she'll say "hearing aid" and she'll tell you to put it in. (p. 12)

When she started daycare at 18 months, they had a lot of behavioral issues and they didn't really flag them to me, like I wasn't aware that there was a problem until she got the hearing aids, and then they said, oh, she's totally different, she doesn't do this, this, and this. (p. 19)

## Parents' Concerns About Development

### Understanding the impact of hearing loss

Several parents mentioned that it just took time to understand what a mild hearing loss or unilateral loss really meant.

A few felt this was due to limited information at identification. However, others felt it was simply a matter of needing to experience time with the child to truly grasp the meaning of mild hearing loss. Some parents talked about moving from a point of little or no concern to a greater awareness of the impact or potential impact of hearing loss. Other parents were concerned that other individuals in the child's learning environment did not grasp the potential effect of the hearing loss. Overall, for many parents, as their comfort level increased and with observations of their child's development, their concerns about the effect of hearing loss decreased.

So the fact that people were telling me mild, I didn't know what that meant. I was hearing 'hearing loss', what mild means versus what severe means,... but nobody could explain what mild meant for my child. When they told me she needed to be aided, than that's when ... oh my, this is more severe than I thought. I didn't know how it would impact her life, ... I didn't even assume she would need hearing aids, like I didn't think it was that bad of a hearing loss. (p. 10)

It took a while for it to sink in, ok she's got hearing aids and she'll probably continue to need them. There's still a chance that in adulthood she may not need them because this is still a critical time where she needs help with her speech but I mean I don't know that I fully understand the hearing loss, I keep wondering about that because ...I thought the hearing aids were supposed to make her start hearing normal and so I just recently learned that it doesn't make her hearing normal, it improves it and helps. ...it's a hearing aid, not a hearing fixer. (p. 5)

...not so much that I shelter her, but in a situation where it is loud, and you know I don't expect her to listen as much, you know I try not to expose her. Like you know, there's sometimes, where I think we're going to skip this birthday party because I don't think it's going to be a fun environment for her. (p. 13)

### Speech-language development

Some parents expressed no concerns about their child's current auditory and communication development while others were more hesitant. For others, even though they were informed based on assessments that language development was within normal limits, they felt they needed ongoing support and reassurance that everything was on track in terms of communication development. Some indicated they found from interactions with other families helpful.

She got discharged, and that was upsetting because I asked the director... I would like a home visitor to come check on us at least once a month so that we could have continuity, like you're dismissing my child at 18 months, she's not even talking yet, like she's not even formulating full sentences, like yes, she has a really amazing vocabulary and she makes eye contact, but anything could happen. (p. 9)

I really felt like I had support and I mean it's great that she was doing so well, but because she was doing so well, they kicked us out of the program after a year, and I feel now that I wish that they would keep us on, even if it was once every 7 months, just to see if we're still developing as well. (p. 3)

We didn't have a lot of people to talk to until we, we just had the infant hearing, and then I set up my own hearing loss website. (p. 7)

### Long-term impact

Notably, there were several comments from parents about the long-term impact of hearing loss. In particular, parents raised concerns about how it would affect their child's learning in school. A few parents shared their fears that hearing loss would worsen and affect their child's development.

...the thing I'm worried about, is when she does go to school, it would be nice to have some kind of support for that, you know. But

I'm nervous, am I telling the teacher the right things? Am I asking the right questions? (p. 3)

Well, that's our concern now, is it going to get worse.... But you always have that concern. But, I'm grateful that it's one ear, and I'm hoping that it will remain that way. (p. 2)

## Discussion

Up to one-half of children identified with permanent hearing disorders have mild bilateral or unilateral loss (Fitzpatrick et al., 2014; Russ et al., 2003). This study allowed us to invite the perspectives of parents of a contemporary cohort of children identified with mild bilateral or unilateral hearing loss before their third birthday. This study is important because questions remain about how best to service these families in the light of the uncertainties related to the impact of milder forms of hearing loss. Parents' comments from interviews were analyzed to generate a better understanding of their experiences in the early stages of learning of hearing loss and their perceptions of their child's functioning.

Our research supports concerns and previous work that regardless of the degree of hearing loss, parents are very much affected by the identification of a hearing loss. These parents were positive about screening and pleased to know about the presence of hearing loss early in much the same way as parents of children with more severe losses (Fitzpatrick et al., 2007; Young & Tattersall, 2007). However, our interview data suggest that changes and fine-tuning are required at the practice level including more support and clearer guidance for families in the early stages of learning about hearing loss.

Parents' accounts of their experiences throughout the screening and diagnostic stages were highly variable with more than half sharing negative aspects or concerns about the process. Our finding that professional attitudes greatly affected how parents view this process is consistent with research in England by Tattersall and Young (2006), where professional communication and manner was an important predictor of parents' perceptions of their early experiences around the identification. With this particular group of parents of children with milder losses, there were two dimensions that are highly applicable. It can be more difficult to draw conclusions about very mild hearing loss in infants especially in the presence of middle ear disorders, resulting in inconclusive audiologic assessments. Secondly, the dismissive nature of professionals' comments about the seriousness of the hearing loss was particularly bothersome for some parents. This finding is an important reminder that learning of hearing loss greatly affects parents regardless of its audiometric nature at least until they have some sense of how it will impact the child and family. Our data confirm that parents feel vulnerable and need considerable support and information about the meaning of hearing loss in these early stages, irrespective of the nature of the problem.

Learning about the presence of these milder hearing losses at an early age raises questions about amplification. The need for amplification was particularly disconcerting for some and confusing the issue was the limited information for parents about the benefits of amplification. Several parents pointed to decision making about amplification as a major issue/concern. Parents expressed confusion when there were mixed messages from audiologist and physician. Previous reports/reviews have highlighted the challenges of developing clear guidelines for amplification and intervention for these children (Holstrum, Gaffney, Gravel, Oyler, & Ross, 2008; McKay et al., 2008; Tharpe, 2008). Our previous research has shown that clinical decisions prior to

screening were highly dependent on age of identification with children at later ages more likely to receive amplification shortly after identification (Fitzpatrick et al., 2010, 2014). Walker et al. (2013) recently reported on patterns of amplification use in 272 preschool age children with mild-to-severe hearing loss. Parent comments from our interviews seemed to fit with the Walker et al. (2013) findings that children with milder hearing loss as well as young children used amplification less consistently than older children and those with more severe loss. Previous population-based research from our lab showed that although amplification was recommended for the overwhelming majority of children with mild bilateral and unilateral loss both in pre- and postscreening cohorts, amplification was not used or inconsistently used in 30–50% of children (Fitzpatrick et al., 2010, 2014).

Taken together, these findings highlight the need for ongoing counseling to support parents as they learn what hearing loss means and how it impacts their children. Our conclusions are consistent with the work of Moeller et al. (2009), which was based on questionnaires with mothers of seven children with mild to moderately severe hearing loss. Parents seem to require considerable support in adapting to caring for a child with hearing aids. In particular, these data suggest that parents need guidance, clear communication, and specific support in achieving more consistent hearing aid use for children with milder losses. The results from these studies coupled with our parent interview data indicate that strategies and guidance to facilitate hearing aid use is an important area for future investigation. Amplification use in this unique young population of children specifically with milder losses is currently being examined in our larger study from which this sample was drawn.

As parents became more familiar with hearing loss and observed the limited impact on their child's language and social development in the early years, their concerns about the effects of hearing loss on communication development decreased. Many expressed little or no concerns about their children's speech and language development based on their own observations and assessments from their intervention programs. However, there were lingering doubts about what effects hearing loss might have at school and about the long-term course of their child's hearing loss. It was clear that for all parents, whether there were specific concerns about their child's language or not, hearing loss was not far from their minds as they observed their children's auditory and communication development.

Parents brought forward concerns related to early care of their children with mild bilateral and unilateral hearing loss that require further attention. To date, most of the discussion about mild bilateral and unilateral hearing loss pertains to children who were diagnosed at late preschool or school ages. An important difference of this cohort compared with previous studies of children with mild bilateral or unilateral hearing loss is the early age of identification and early access to amplification. Considerable attention has been accorded to parents' perceptions of their needs for support throughout the early years. However, based on this study, it seems that further investigation is warranted to determine how best to support parents of this new generation of children with milder hearing losses. One important consideration in developing support programs compared with children with more severe hearing loss is that many families are not seen as frequently in early intervention services because milder hearing loss has less impact on language development.

One advantage of this study is that children were drawn from one province where a systematic and well-developed newborn hearing screening and intervention protocols are in place.

However, despite this, parents' comments suggest considerable differences between regions. It is possible that practices for these children are less well defined than for those with more severe hearing losses. Another strength of our study is that it is one of the first to include the experiences and views of parents of early diagnosed mild bilateral and unilateral hearing loss. Therefore, although parents were asked to recall memories of the initial diagnostic and intervention process, they were not far along in the process as they continued to provide care for their preschooler. No parent had more than 2 years of experience with hearing loss in the study.

One limitation of this study is that parents were generally highly educated and their experiences and views may not necessarily reflect those of parents from different socioeconomic and language backgrounds. In addition, our findings are limited to the views of parents with normal hearing as no parents with hearing loss enrolled in the study, although they were not excluded based on study criteria. While having children from one province with a clearly defined protocol was a strength, the study is at the same time limited in that some findings may not be transferable to areas with different early intervention protocols. Therefore, caution should be exercised when interpreting the findings, as they may not be transferable to other settings. It is important to note that in these publicly funded programs, screening, diagnostic, and intervention services were available to all children. Although, we attempted to capture both the positive and more difficult aspects of parents' experiences, it is possible that in this type of interview format, parents tended to recall and provide more information about concerns or negative aspects surrounding services, rather than the positive aspects of professional care. Although qualitative data provide rich insights into parents' perceptions, sample selection and small sample sizes means that the findings are not intended to be representative.

Improving care for all children with hearing loss is a goal of population-based newborn hearing screening ([Joint Committee on Infant Hearing, 2007](#)). Early identification of any hearing disorder is intended to facilitate early development. Our study is one of the first to examine specifically the perceptions of parents of children with early identified milder hearing loss. It is clear that parents appreciate knowing about their child's hearing loss early. However, learning about hearing loss brings new questions and parents require clear guidance and support in the process of caring for their child to reap optimal benefits from society's investments in early identification.

## Conflicts of Interest

No conflicts of interest were reported.

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## Appendix

### Parent interview guide: mild bilateral/unilateral hearing loss

#### Purpose of interview

I am meeting with parents to better understand the impact of the early identification of milder forms of hearing loss through infant hearing screening on the family. I will be talking with several parents of young children with hearing loss about their experiences with the identification of the hearing loss. I would like to hear about how you learned of your child's hearing loss and how you think it has made a difference for you and your child, your perceptions of how your child is doing. I would also like to hear about your needs once you learned that your child has a hearing loss and about what kind of services you feel were/are the most appropriate in guiding you in developing your child's communication.

#### Procedure

I will ask you questions to guide our conversation but feel free to talk about your experiences and to add any information you feel is important. Please don't hesitate to ask questions.

1. Tell me how you found out about your child's hearing loss.  
Probe: Tell me about the process from screening to confirmation of the hearing loss. How many visits? How long before there was a definitive confirmation?  
Did you have any concerns about your child during the process?

2. What impact do you think screening (or not) will have on you and your child?  
*Probe: How has learning of the hearing loss through screening been beneficial or negative for you and your child?  
 How are things better/worse for you and your family because of the early diagnosis?  
 How do you think it might be different if your child's hearing had not been screened?*
  
3. I am interested in understanding your needs when your child was first diagnosed and then later after the diagnosis?  
*Probe: What kind of information from service providers did you find helpful in the beginning?  
 What information or guidance did you need in the days/weeks/months following the diagnosis (for example, after the confirmation / hearing aid fitting)?  
 What kind of supports did you need, for example, social worker, therapist, family?  
 What supports/information did you receive? What else was/is needed for you to help your child develop?*
  
4. Tell me about what has happened since the confirmation of hearing loss?  
*Probe: Was your child fit with amplification. At what age, how long after confirmation?*

*How are things with hearing aids? Does amplification make a difference - hearing/language?*

5. Tell me about any other intervention your child receives because of the hearing loss?  
*Probe: Was the process straightforward? Direct intervention? Parent education?  
 Are you satisfied with the intervention and services received?*
  
6. Do you have any other concerns about your child's development related to his/her hearing loss?  
*Probe: Are his speech and language skills on track? Are there situations where hearing seems to be a barrier?  
 Are there any situations where you observe / are concerned that he is affected by his hearing loss?*
  
7. If you could create a perfect health system for you and your child, what would it look like, that is, what types of services should it provide?  
*Probe: What kinds of professionals, type of setting, and frequency of visits would be helpful?  
 Tell me about the guidance you would like in helping your child with regards to his hearing?  
 What are we (clinics) doing well and what do we need to do better? Do you perceive any gaps in service?*

General information

Location of interview:	Home	<input type="checkbox"/>	Other				
Informant:	Mother	<input type="checkbox"/>	Father	<input type="checkbox"/>	Other	<input type="checkbox"/>	
Screening status:	Screened	<input type="checkbox"/>	UNHS	<input type="checkbox"/>	Targeted	<input type="checkbox"/>	Not screened <input type="checkbox"/>
Screening category:	Well-baby	<input type="checkbox"/>	NICU	<input type="checkbox"/>	At risk	<input type="checkbox"/>	No risk <input type="checkbox"/>
Age of child (interview)	_____		Age at diagnosis	_____		Age intervention	_____
Degree of hearing loss:	Mild	<input type="checkbox"/>	Moderate	<input type="checkbox"/>	Severe	<input type="checkbox"/>	Profound <input type="checkbox"/>
Hearing technology:	Hearing aids	<input type="checkbox"/>	Date of fitting	_____		Cochlear implant	<input type="checkbox"/>
Diagnostic center	_____		Intervention center(s)	_____			
Type of intervention	_____		Frequency	_____			
Other disabilities	_____		Interviewer comments	_____			