Parents' Experiences in a Locally Initiated Newborn Hearing Screening Program

Un programme d'initative locale de dépistage auditif chez les nouveau-nés : le point de vue de parents

Sarah Kelly
Mary Ann Bibby

Abstract

This exploratory qualitative study presents an in-depth look at the experiences of five parents whose children were diagnosed with a hearing loss through newborn hearing screening. The screening was implemented as part of a research project in four health regions in Alberta. The funding for this project covered only newborn hearing screening, with referral to diagnosis. Program restructuring that allowed seamless transitions from screening to diagnosis and intervention services could not be funded, so parents needed to access already existing support services and programs. The parents in this study shared their experiences pertaining to the screening and diagnostic process and their transition to intervention programs. The following three major themes emerged from the parents' stories as they shared their perspectives: (a) experiencing and dealing with the screening and diagnosis, (b) interacting with professionals, and (c) coping and realizing additional areas of need. The findings of the study indicate that the parents experience significant challenges as they navigate the process. The stories of parents provide valuable insights into their own strengths and how screening services, professional interactions, and the process of empowering parents can be improved.

Abrégé

La présente étude exploratoire de type qualitatif examine en profondeur l'expérience vécue par cinq parents qui ont appris que leur enfant avait une perte auditive par le biais d'un programme de dépistage auditif chez les nouveau-nés. Ce programme a été mis en œuvre dans le cadre d'un projet de recherche dans quatre régies régionales de la santé de l'Alberta. Le financement de cette étude assurait seulement le dépistage auditif des nouveau-nés, incluant une référence vers les milieux cliniques. Il ne permettait pas de procéder à une restructuration des programmes visant une transition fluide entre les services de dépistage et les services de diagnostic et d'intervention, de sorte que les parents devaient accéder aux services et programmes déjà en place. Les parents de cette étude ont partagé leur expérience par rapport au processus de dépistage et de diagnostic et à la transition vers les programmes d'intervention. Les trois grands thèmes suivants sont ressortis des témoignages des parents : (a) vivre et de gérer l'expérience du dépistage et du diagnostic; (b) interagir avec les professionnels, et (c) s'en sortir et prendre conscience de besoins supplémentaires dans plusieurs sphères. Les observations de cette étude montrent que les parents doivent surmonter des défis considérables pour franchir les étapes de ce processus. Leurs témoignages permettent de poser un regard utile sur leurs propres forces et sur la manière d'améliorer les services de dépistage, les interactions avec les professionnels ainsi que le processus accordant plus de pouvoir aux parents.

Sarah Kelly, MEd, Ph.D. Candidate
Department of Educational Psychology
University of Alberta
Edmonton, Alberta Canada

Mary Ann Bibby, Ph.D.
Department of Educational Psychology
University of Alberta
Edmonton, Alberta Canada

Key words: parents' perspectives, early hearing detection, hearing loss, locally initiated newborn hearing screening, facilitation to intervention, best practices

New technological advances are shaping the futures of children born with a hearing loss. The implementation of newborn hearing screening (NHS) for all babies is the first step in a process that moves families from screening to diagnosis and then to referral for intervention. Although screening is a necessary component of a comprehensive early hearing detection and intervention (EHDI) program, to be ultimately successful, research from best practices has indicated that it must also be tightly integrated with diagnostics and intervention services (Hyde & Riko, 2000). In Canada, however, only a few areas have initiated province-wide collaborative EHDI programs. In several provinces, NHS is being implemented and funded through local hospital initiatives. In these cases, there is no comprehensive provincial planning. Parents take advantage of existing services that may or may not be coordinated. Park, Warner, Sturgill, and Alder (2006) indicated that even in comprehensive programs, however, numerous obstacles remain in the way of obtaining timely screening, diagnosis, and treatment. Some families still experience a gap between "the ideal" and the "real." A body of knowledge is building on EHDI programs, but little research has explored the experiences of screening in the more individualized initiatives. This exploratory qualitative study asked parents about their experiences within the context of a non-comprehensive screening procedure and contrasted the findings with recommended practice. Parents' stories provided snapshots of their fears, frustrations, and strengths. They shed light on both the negative and the positive aspects of the system, and provided important signposts for change.

Background

The Canadian Context

Over 25 years ago, in the 1980s, a federal task force on childhood hearing impairment surveyed the provinces and territories to document the activities that were in place in the areas of early hearing detection, identification, and intervention. At that time, screening was performed only in high-risk registries. Although technology was advancing, the survey results indicated a lack of standardized screening tools, a lack of audiologists, and other system barriers (Durieux-Smith & Stuart, 2000). In 1999 in another survey, Brown, Dort, and Sauve (2000) found that in spite of more advanced technology, only 10% of Canadian birthing hospitals had any type of hearing screening for newborns. In other North American contexts, research indicated initial concerns about cost recovery, the availability of trained professionals, and the quality of outcomes for children. By 1998, the implementation of hospital screening was determined to be "feasible, beneficial and justified" (Mehl & Thompson, 1998, p. 1).

In 2000, the Canadian Association of Speech Language Pathologists and Audiologists (CASLPA) and the Canadian Academy of Audiologists (CAA) published a position statement that recognized and supported the need for "the establishment of an integrated system" (Durieux-Smith, Seewald, & Hyde, 2001, p. 140). Durieux-Smith et al. recommended that this system include hearing screening for all babies; seamless transitions through screening, diagnosis, and early intervention; ongoing surveillance; educational components; professional development; and uniform provincial and territorial registries.

At the same time, CASLPA supported the recommendations (see below) of the American Joint Committee on Infant Hearing ([JCIH] 1994, 2000), the American Academy of Pediatrics (1999), and the National Institute of Health (1993). The 2000 JCIH position statement suggested a re-evaluation of existing diagnostic and support services and recommended eight principles to guide the implementation of comprehensive EHDI programs: (a) Infants should be screened before 1 month of age; (b) diagnostics should occur before 3 months; (c) intervention should begin before 6 months; (d) children passing the screening but identified as at risk should be monitored; (e) families should have the right to make informed decisions; (f) the results from the screening should be protected as carefully as any other health information; (g) regions should monitor their programs' effectiveness; and (h) regions should monitor their programs to ensure quality, practicality, and cost effectiveness (JCIH, 2000).

In 2005, the Canadian Working Group on Childhood Hearing (CWGCH) published a document to be used as an "evidence-based resource on early hearing and communication development (EHCD)" (CWGCH, 2005, p.1) for provinces that were implementing EHCD programs. The CWGCH chose the term "Early Hearing and Communication Development programs" to emphasize the goal of communication development.

As of August 2007, the government is offering comprehensive funding for EHDI program development in some provinces such as Ontario, New Brunswick, Nova Scotia, and British Columbia, but in other provinces, hearing screening is still being initiated locally and is not provincially coordinated with other diagnostic and intervention services.

The Screening Process: The First Step to Support and Intervention

The screening process, whether as part of an EHDI program or as a local initiative, follows well-established guidelines and protocols. The infant is usually first screened in a two-stage process 24 to 48 hours after birth with automated technology that is "objective, physiologic, reasonably accurate, non-invasive, quick, and inexpensive" (Hyde, 2005, p. S72). The screening can be done while the child is sleeping or quiet. A 'refer' result from the screening necessitates follow-up with diagnostic audiology to determine the type of hearing loss, which ear is affected, and the degree of the hearing loss (Widen, Bull, & Folsom, 2003). A common goal is to complete audiometric testing by about 3 months (Hyde, 2005), and an audiologist must interpret the results (Hyde & Riko, 2000). Some parents are also referred to an ear, nose, and throat specialist for a medical diagnosis. The parents' own insights and

observations can contribute to the diagnostic evaluation (Hyde & Riko, 2000).

The goal of a "best practices" EHDI program is to facilitate the child and family's access to the most appropriate follow-up, counselling, and intervention services within the 6-month time frame to support the family's ability to develop their infant's communication and language skills, to enhance the family's understanding of their infant's strengths and needs, and to promote the family's ability to advocate on behalf of their infant (Gracey, 2003). In contrast, a locally initiated screening procedure usually encourages professionals to follow procedures and access services that may be well established but not coordinated.

The Parents' Context

If a child is diagnosed with hearing loss, this has a significant impact on the whole family. Approximately 90% of infants born with a hearing loss are born to hearing parents (Northern & Downs, 1991). Newborn hearing screening allows children's hearing loss to be detected soon after birth, much earlier than what has historically been the case. This can be a very emotional and vulnerable time, particularly for new parents (Benedict & Raimondo, 2003; Gallagher, Easterbrooks, & Malone, 2006; Sjoblad, Harrison, Roush, & McWilliam, 2001). Not only must parents adjust to the birth of a new family member, but they are also asked to come to terms with the diagnosis and begin to make decisions that will have a significant impact on their child's future development and education. The majority of the parents have little, if any, experience with hearing loss (Vaccari & Marschark, 1997). The parents have "no experiences to draw upon, no expectations to refer to, and often, no close family or personal friend to consult" (McCracken, 2001, p. 121). Families must "face the challenge of trying to visualize the child's future with at best a poorly informed model of what this might look like" (p. 122). The families must also come to terms with the fact that their homes become staging grounds for various counselling, support, or teaching activities on a weekly basis (McCracken, 2001). They have to open their doors to numerous unknown medical professionals and support workers. Where the child is born also determines accessibility to the appropriate diagnostic facilities and support. Families "have little choice in this matter, being subject to the local arrangements and provisions" (McCracken, 2001, p. 122).

Context of the Study and Objectives

The participants in this study were parents who had experienced NHS in one of four provincial health regions in Alberta. The initiatives in these regional birthing hospitals were part of a research project that had been established specifically to investigate only this initial screening and diagnostic phase. The principal objective of the project was to identify infants with hearing loss by 3 months of age. The project assumed that after the identification of hearing loss , parents would then be referred to intervention services (Dort, 2000). The aims were to screen a minimum of 95% of all newborns, to establish a tracking system to ensure follow-up, and to diagnose hearing loss. Funding for this project was limited to developing and implementing screening procedures (Alberta Universal Newborn Hearing Screening Project, 2000).

Screening protocols developed in line with well-established guidelines and recommendations for diagnostics and intervention were distributed to appropriate professionals. However, the exact mechanisms for the implementation of the guidelines was left up to the local professionals (Alberta Universal Newborn Hearing Screening Project, 2000).

Little research has been conducted with parents who have experience with locally initiated screening procedures. The present study elicited the stories of five parents, which shed light on factors unique to their experience. Their insights and ideas for improvement are essential to our understanding of the ways in which professional behaviour and system challenges affect the lives of families.

Methods

Recruitment and Description of Participants

We used a basic interpretive approach (Merriam, 2002) and an open-ended interview technique (Patton, 2001) to explore the experiences of parents and, ultimately, to gain insight into their needs. The selection of the participants was based on purposeful sampling (Patton, 2001). The criteria for participation specified that the parents would (a) be hearing and (b) have had their infant diagnosed with a hearing loss in the new screening programs . Three of the four health regions agreed to initiate participant recruitment. The coordinators contacted parents, informed them of the study, and asked them whether they were interested in participating. Those who expressed interest were presented with appropriate information about the study. Of seven families who agreed to participate, only four could be interviewed. Three families were unable to participate because of relocation, family death, and medical considerations. In three of the four participating families, the mothers were interviewed. In the fourth family, both the mother and the father were interviewed, The parents provided "thorough, in-depth, powerful and information rich accounts" (Patton, 1990, p. 182) of their experiences.

The age at which the infants were first screened ranged from birth to 3 ½ weeks, and they were officially diagnosed at between 6 weeks and 9 months of age. The age of each child at the time of the interview ranged from 1 year to 3 years. John and Samantha (all names changed) were initially diagnosed with a sensorineural hearing loss. Ella and Joey were diagnosed with a conductive hearing loss. The degree of the children's hearing loss ranged from mild to profound; two children had a health concern in addition to their hearing loss. An introduction to the families is presented further down.

Procedures and Data Analysis

Following established procedures for facilitating participation and encouraging discussion (Merriam, 1998; Rubin & Rubin, 2004), we collected data through in-depth, open-ended, semistructured interviews that lasted from 60 to 90 minutes. Before the interviews, we developed a guide (Patton, 1990) that was based on issues that were highlighted in the literature as being relevant to the NHS experience. The questions were open-ended to allow other relevant issues and insights to emerge spontaneously. We audiotaped and transcribed the interviews verbatim and sent the transcripts to the parents for feedback. Three different research ethics boards - one from the university faculty in which this research was conducted and the others from the health regions - reviewed and approved the research protocol.

Analysis of the interview data followed procedures appropriate to the identification of themes (DeSantis & Ugarriza, 2000; Merriam, 1998; Miles & Huberman, 1994). We marked or highlighted "interesting" and "significant" issues or quotations in the margin with comments (Barnard, 1997). These highlighted sections were then coded and merged into themes. Following the analysis, we contacted the parents for verification. In addition to their transcript, we sent them a summary that described the topics discussed and identified the themes of the interview so that the parents could "clarify and amplify the themes that had emerged during the first interview" (Corcoran & Stewart, 1998, p. 91). We conducted the follow-up discussions by mail and over the phone.

Introduction to the Parents and Children

Rachael told us about some very difficult experiences with her son Joey, who was born with a cleft palate and was slightly over 1 year old when the interview took place. She described dealing with the confusion about the screenings, the diagnosis and multiple appointments. She had mixed feelings about her encounters with different professionals. She shared her frustrations with these experiences.

Susan spoke eloquently about the challenges she encountered in not being able to confirm a conductive hearing loss until Ella was 9 months old. Ella was 2 years old at the time of the interview, and since the diagnosis, Susan had been able to obtain "good" information and support from "home-based development coordinators."

Julie's son John was born just before NHS was implemented in her hospital. Julie told us about "being distressed and having to convince" professionals to arrange for screening. After two screenings, John was diagnosed with a profound sensorineural loss at 7 weeks. At the time of the interview, John was about 3 years old. Julie talked about her challenges and successes in accessing a variety of professionals for assessments and service.

Morgan and Paul shared different perspectives on their experiences with Samantha. Paul's perspective was unique in that he himself had a hearing loss. Samantha was 17 months at the time of the interviews. Both parents spoke about difficulties that they encountered during several screenings and about not receiving confirmation of a permanent conductive hearing loss until Samantha was about 7 months old.

Findings

Dealing With the New Procedures

The screening process. The screening process itself left the parents with mixed feelings. All of them had "heard something about it" before it was done, through either their doctor or another professional. Morgan had been told by "a hearing screening nurse who explained how it all worked and what they were going to do, [so I was] fine with that information and really appreciated it." Susan said that she "thought that the experience in itself would be cool. I thought it was a great thing."

Getting a 'refer' result, however, precipitated anxious responses from the parents. They received the information from the audiologist, the nurse, or the assistant who had done the screening. All reported that they were "confused" and "uncertain" about what it meant. Julie explained that the terminology caused her concern:

John received a 'refer' on his second testing. *"I said, 'That means he failed.' All she would tell me was, 'Well no, no, that doesn't mean he failed. It just means that we need more information.' So I didn't really get anything from her."*

Rachael felt that she was not provided with adequate information about the screening process:

"[The screener] just came in, tested, and she just did it again and again and again. She just handed me a little pamphlet . . . but she didn't fill it in. She said, 'He didn't pass. He'll need further testing.' She just didn't know what to say to me."

All children underwent at least three screenings. The parents recalled being told that the equipment was either "acting up" or "not working properly," and Morgan was told that "we are going to see if we can get a different machine; come back in a couple of weeks again." Susan was told that her infant Ella was either "too mucousy" or "rattly," which would require further screening. It was difficult for the parents to bring their infants for multiple screenings. Susan told us:

"They did not say Ella might have a hearing loss. I was really, really anxious and frustrated, very frustrated, very hesitant about taking her in again. I just wanted to forgo all the little steps and go for the main testing. I understand that there is a process to follow too, but it was so frustrating as a parent to sit back and hear excuses like my baby was breathing too loud."

Even Paul, who had personal experience with hearing loss, found that the process of multiple screenings had a big impact upon his hopes and expectations:

"In my mind, I just kind of ruled it out. It could be a hearing loss, but I bet more on thinking that it was equipment malfunctions [or] environmental factors. Maybe something's just not quite right, but maybe Samantha is really just fine."

Waiting for a diagnostic referral and then waiting for an appointment with the audiologist put Morgan and the other parents into "a little bit of a no-man's land." Susan reported that "not knowing drove me nuts." The wait time ranged from 2 weeks to 9 months for the parents in this study, but Julie said, "It didn't matter how long it lasted; when you're waiting for something like that, it is forever."

Receiving the diagnosis. Receiving the diagnosis meant that the parents had to balance deep emotions with receiving new and distressing information. All of the parents described the shock and stress of the diagnosis of their child's hearing loss.

Susan: "*I just thought . . . Oh my God, this is happening to me . . . what does this mean? I have had two healthy children up until now, and now I'm going to have one that is hearing impaired. And of course the panic button's been hit.*"

Morgan: "*Right away I remember thinking . . . I think I should have a multitude of questions to ask, but I just couldn't think any more at that point.*"

Rachael: "*All you're thinking is, Oh my God, my baby is deaf! That's the only thing that I thought: . . . Oh my God, oh my God!*"

Paul: "*Well, it's like a death; it's really like a death. Sam is still alive, of course, but to have some of your hopes crushed . . . with that comes the experience of loss, and with that comes the experience of grieving.*"

Julie: "*You go back and think, What have I done? What did I do while I was pregnant that would cause that? . . . Oh God, is that what did it?*"

Receiving "too much" or "not enough" information. Receiving "too much" or "not enough" information was a thread that connected the stories of the parents. They had different experiences, both positive and negative, with the amount and quality of information that they received from the professionals after the diagnosis. Terms such as "profound hearing loss," "deaf," and "hearing impairment" were confusing because, as Julie said, "not knowing anything about hearing loss, [those terms] didn't register for me. I left feeling really uninformed." Julie reported difficulties getting the information and support that she needed at the diagnostic stage:

"*I was like, well, what do I do? . . . The hospital that we dealt with in [the city] . . . and the doctor didn't even seem like they had the time to deal with us. They were just so busy. . . . And I know [my husband] got really mad and stormed out because we had been down there for three days, and we didn't really get anywhere with anything. The only thing we found out is the things that we already knew . . . that he had a profound loss and that we should get hearing aids and start sign language.*"

Rachael, Susan, and Morgan, on the other hand, expressed appreciation for having received "a lot of information up front about . . . options." Rachael found this information helpful, "especially when you are so concerned about it. It's such a shock; you don't know what to expect. As you deal with it, you get more comfortable to a certain extent. That's just the way it is." But the parents also talked about feeling "overwhelmed" or like "spinning circles" as they strived to keep their emotional balance. Susan and Morgan expressed this as follows:

Susan: "*[The home base development coordinator] gave it all to me to the point where I was a little overwhelmed because it was so much. But on the opposite side of things, it calmed my nerves down enough to actually be able to absorb things, and that's what I needed at the time.*"

Morgan: "*My audiologist gave me [a lot of information]. At the time, I felt quite okay with it. . . . There was a lot of information at that point that's thrown at you, and not in a bad way, but just because these are the things you need to do; these are the steps you need to take; here's a folder of information. And you can get online with these organizations and support and that kind of thing. Just with the whole nature of everything that had been going on in our lives, I went home and I put it all away [laughs] because I was just feeling personally overwhelmed with everything, and I needed to just slow down. I felt like, I will take out this book, one piece of paper at a time, when I am ready to take it out and read it, but don't push me right now.*"

Even though Morgan and Paul knew about the hearing loss, Paul reported:

"*We just didn't get on the ball with it partially because we just were so overwhelmed with everything else that had just happened. Looking back, I wish that, at the time, I had pursued that more. . . . I think Morgan had to give me a pep talk, and . . . I had to kick myself in the pants. My ignoring of the issues, the fact of her hearing loss . . . choosing inactivity, that's not helping her at all.*"

Julie shared a positive experience when her audiologist helped her with the overwhelming information that she received:

"'*I'll let you go home now, and I'll give you a call tomorrow afternoon. . . . It's a lot for you to deal with right now. I'll just give you a chance to come to terms with it.' . . . And that's what she [the audiologist] did.*"

Interacting With Professionals. After describing the screening process, the parents shared their perspectives on interacting with the professionals, which included issues of communication. They felt overwhelmed by the number of professionals who became involved in the care of their child. At the same time, they sometimes felt unsupported as they transitioned from the diagnosis to intervention programs. They were concerned about mistakes that were made, and information that was sometimes inappropriate or inaccurate.

In sharing their stories, Rachael, Susan, and Julie highlighted communication issues. Rachael addressed the frustration that she felt when there appeared to be confusion about Joey's hearing loss. At first his hearing loss was diagnosed as sensorineural, but about six months later, after tube surgery for ear infections, his hearing was found to be normal:

"*They figured it was his middle ear or his inner ear and they weren't sure, and it's just, 'He is deaf.' But as it turns out, it wasn't that the test said he was deaf; it was the doctor being too rushed or negligent to look at the chart.*"

Susan and Julie also talked about difficulties with communication:

Susan: "*I know a lot of professionals nowadays are scared to tell you what they think; they only want to tell you what they know. But I honestly think that, if they think it's a hearing loss, then say it may be. 'Further testing is needed' . . . that's all it would have taken. . . . I think they have to take at least that into consideration: not the testing itself, but how do you convey the results to parents or not convey, in my case?*"

Julie: "*It was almost like, 'We have told you that your child has a hearing loss. We have told you what to do, what more do you want from us?'. . . [Even the doctor] didn't give us any time really.*"

At a time when the parents were adjusting to a new member in their family, they had to open their doors to unknown professionals and accommodate numerous medical and home visits within the context of finding out about hearing loss. Members from nine different specialities were involved in the care of the children of the four families in this study. Rachael dealt with seven professionals; Morgan and Paul, as well as Susan, each encountered six; and Julie interacted with 10.

Susan "*had two people from [an intervention service] coming in once a week, and it was just . . . so overwhelming.*" Morgan's statement captured the feelings of the other parents:

"*There really was a time when things got really confusing because you are working with so many professionals. Between the speech-language pathologist, the public health nurse, and three different audiologists, after a while I was asking questions like, 'I don't know if I am supposed to contact these people myself or whether they contact each other or whether I am supposed to phone the S-LP, or are they going to make that connection for me?'*"

The parents also commented that at times they felt unsupported, unassisted, and "left to their own devices" in trying to access intervention services. Rachael came across services "just by fluke," and Susan felt very "lucky" when "she caught sight of a poster advertising services." Yet, even though the parents talked about the difficulties that they had in trying to access services, Julie and Susan also reported relief once they were connected with a supportive professional:

Julie: "*You didn't know where to be going and you didn't know what to be doing. . . . You really had nowhere to go and no one to turn to. . . . [But] I've thanked the audiologist there, oh my God, a million times. . . . I used to speak with her every day and found out pretty well everything I needed to know. She set it all up [for appointments] and visits. . . . She was so helpful, and she still keeps in contact with us after 3 years.*"

Susan: "*If I needed to know something, I could phone and leave [the home-based development coordinator] a voice mail, and she would get back to me even after hours. . . . There was no waiting for days . . . it was almost immediate. If she wasn't in the office, she'd call me as soon as she got the message. If she didn't know the answer, she'd find out. She was right in there, and had she not been . . . I don't know where we'd be today.*"

However, the information that the parents received was mixed. Some was useful and appropriate, but some was not. Paul and Morgan were told that "because Samantha was still a newborn, [intervention] wasn't really pertinent right now." Similarly, a speech pathologist told Rachael that her child was "just too young. . . . We won't come out until he's at least 18 months." Paul said that his own audiologist later admitted not knowing about the best amplification for babies: "It wasn't a fault or oversight . . . they just did not know." In addition, professionals also told these parents that their child would "have no speech; he's going to need hearing aids and sign language." Julie, on the other hand, was informed that "the recommendation is to amplify. His exact words were, 'From our standpoint, we expedite amplification,'" and there was "no mention of alternatives, neither sign nor cochlear implants."

Coping and Identifying Additional Needs. After having their child diagnosed with a hearing loss, the parents talked about becoming a "parent of a child who is deaf" and their needs for support in this new role. During the time of finding out, Morgan was grateful for "a lot of family support. "Both of our families are well aware and very supportive, and there were definitely other Christians from our church around us who were a huge support." Susan too said, "I don't know if I would have been able to keep it together had it not been for my mom." Rachael, however, reported that "at first even family didn't want to hold him, didn't want to baby-sit him because of his hearing aids." Julie felt isolated living "away from home. . . . When you don't know anybody, you have nobody to call, and you have nobody to talk to."

When we asked the parents how they were able to obtain additional help, both Rachael and Julie talked about accessing the services of a genetic counsellor when they became pregnant again:

Rachael: "*There was a 25% chance that I could have another child with a hearing loss, but I was like, 'At least I know what I'm dealing with.' But I was still like, 'Phew! That's a lot to deal with!'*"

Julie: "*We did find out it was genetic; it was both on my side and [my husband's] side. Both of us are carriers, but there is no history on either side. . . . It was like winning the lottery that you just got two carriers together. . . . My new baby is 8 months old now, and I've had her tested three times because I am really paranoid, but her hearing is fine.*"

Morgan and Paul: "*(We) both would have appreciated the more personal services of a counsellor who can deal with parents of children with a disability . . . just to help us through some of that grieving process and be where we are at and explain how to move on from there. . . . Access to someone who would be up on the latest research and technology and programs, but who can also guide parents through their own thoughts and emotions and help them be the best support they can to their children with disabilities. [That] would be really helpful, really helpful.*"

Each one of the parents expressed a need to access "veteran parents" who had been through the process before and who could explain what the experience was like, what to expect, and what the possible outcomes were. Paul wanted to go to "seminars and workshops and start talking to other parents." Rachael and Morgan concurred:

Rachael: "*[It] could have saved a lot of stress, a lot of not knowing, and especially having someone come in who's dealt with hearing impaired children and who's taught them or who's been a mother, or somebody who's first hand, not somebody who's read about it, because [those professionals] don't really understand.*"

Morgan: "*I think it would have been good for me to have some one-on-one interaction with other parents who have also gone through this same thing. . . . It would have been a comfort at that point.*"

Julie, on the other hand, had positive experiences with other parents. She found e-mail communication particularly helpful:

"*That was one of the biggest things that I found great down here, was that they put me in touch with everybody that was going through the same thing that I went through. They did it in a way that was helpful, because it's not that easy to pick up the phone and talk about it when you are first going through it, so they did it through e-mails. I e mailed a lot at 2 or 3 in the morning when you couldn't sleep, you couldn't call anybody, and I used to e mail people and ask, 'How did you get through that?' or 'How did you deal with this? What did you find was the best way to go about it?*'"

Discussion

In viewing the parents' stories as "of-the-moment-evidence" (Young & Tattersall, 2007, p. 216) and as remembered snapshots of their reality, and in discussing the relevance and importance of these findings, readers must be mindful of the context of the parents' experiences. Funding for this project focussed predominantly on the screening initiative so the referral and intervention procedures relied on existing services in the province. Fitzpatrick, Graham, Durieux-Smith, Angus, and Coyle (2007) noted that in Ontario, local hospitals had begun screening before a province-wide strategic program was developed. Some of the seven children who participated in their study had been "screened through [these] local initiatives" (Fitzpatrick et al., 2007, p. 105). In most provinces such local screening initiatives have been the forerunners of province-wide program development. Where province-wide funding for comprehensive program development is not in place, professionals struggle with decisions such as whether or not to begin a screening program without additional supports in place.

It is interesting to note, however, that even in comprehensive programs, parents still experience difficulties. Mazlan, Hickson, and Driscoll (2006) described these as "service shortfalls" (p. 253). Park et al.'s (2006) survey of 108 families of pediatric patients in a comprehensive program also revealed difficulties that were experienced as a result of information sharing, multiple screenings, and wait lists for diagnostics. Nonetheless, the parents in the present study highlight the pitfalls of developing local initiatives without comprehensive professional collaboration.

The Ongoing Need for Education and Training. The ongoing need for education and training is a thread that ties the experiences of the parents together. Their stories about perceived mistakes and misinformation reveal a critical need to bring professionals up to date in terms of new developments in early identification and intervention. There may be a tendency to believe that because there is an infrastructure for the diagnosis of and intervention for hearing loss, that all of the professionals have current skills and knowledge. The parents have alerted us to the fact that we cannot take this for granted and that education must be ongoing, especially in light of technological advances.

The parents in this study shared their feelings about their interactions with the numerous professionals who had entered their lives. All of the parents would have preferred less ambiguity and more sensitivity in what and how they were told. The professionals conveyed understanding and empathy, or lack thereof, in many ways: through their use of terminology and language, in the amount of time that they spent with the parents, in their ability to listen to the parents' concerns at the time, and through the growth of trust. This happened at different stages: at the screening where the professionals told the parents about the 'refer' result, when the parents received confusing messages about the process itself or about hearing loss, and when they received information about the diagnosis and what would happen after. Professionals have long been aware of the importance of communicating with parents of young children in supportive and empathetic ways. Tattersall and Young (2006) concluded, "In fact, professional communication and manner are the most significant predictors of parents' experiences in the NHS program" (p. 33). Young and Tattersall (2007) discuss the changes brought about by the implementation of newborn hearing screening, such as institution-initiated detection, a compressed timescale between birth and diagnosis, and the effect of the early diagnosis on the development of the relationship between parent and child. In the context of these circumstances, the parents remind us that education must also include training that allows all professionals to interact in the best possible way with parents as they move through one of the most difficult stages of the process. The parents' stories illustrated the importance of professionals' knowledge, impartiality, and ethical conduct in their presentation of information about best practices in intervention.

It is also important to acknowledge that some parents may not always hear what professionals tell them. Parents may pick out parts of a message, or they may get stuck on key words. This underlines that EHDI programs must be structured to allow parents to receive information multiple times and in various formats.

Furthermore, the parents in the present study stressed

the importance of detailed pre-screening information. Weichbold, Welzl-Mueller, and Mussbacher (2001) concluded that parents who are informed about the screening tend to view the process more positively. Other findings indicate that the more informed that parents are about the screening, the higher their acceptance of the screening and the lower the maternal concern about the results (Hergils & Hergils, 2000; Weichbold et al., 2001). However, Davis et al. (2006) found that communication about screening is often limited. For the parents in this study, more detailed information about the screening and the meaning of a 'refer' result might have improved their understanding and alleviated some of their fears.

New Procedures. In discussing the importance of the findings, it is important to remember that the parents experienced screening at the beginning of its implementation in birthing hospitals where "seamless transitioning" and "essential supports" had not been the focus. It is possible that some of the procedural difficulties will be resolved.

The parents expressed concern and worry about the need for multiple screenings because of difficult testing circumstances or to rule out faulty equipment. Repeated screening may be a problem unique to NHS procedures. In fact, most protocols recommend a minimum of two screenings to achieve low false-positive rates (Hyde, 2005). Their occurrence, however, and the degree to which they impact parents can be expected to vary. Differences in parents' perspectives on these procedures may depend upon the extent to which each province has been able to implement the guidelines that the JCIH (1994, 2000) has set out, that CASLPA (Durieux-Smith et al., 2001) has supported, and the CWGCH has reinforced and further developed (CWGCH, 2005).

Careful planning for, developing, and organizing "seamless transitions" are part of these best practice guidelines and necessitate comprehensive province-wide collaboration among professionals. The parents described the difficulties that they faced when there was no comprehensive plan in place . The wait time for the parents of these children ranged from two to nine months, but no matter how long it was before the children were diagnosed, the parents felt the stress of "being in a no-man's land." In one case, the diagnosis was not reached until nine months of age, which defeats the purpose of the NHS. In recognition of the importance of developmental milestones, recommendations for EHDI programs call for screening before 1 month of age, diagnosis before 3 months, and intervention before 6 months. Transition protocols should be in place to facilitate the path to intervention. In many locations, a comprehensive program may require restructuring the health care system to allow parents to access intervention services, audiological and medical management, and family counselling immediately (Mencher & DeVoe, 2001). Access may depend on many factors, such as the number and quality of diagnostic and intervention programs that are already in place for infants, the availability of trained professionals, the geographic location of birthing hospitals and diagnostic centers, the availability of and access to funding, the ability of each province to centralize and share expertise, and the sophistication of "information systems to track and facilitate timely delivery of services" (Hyde, 2005, p. S72). The findings from this study show that although appropriate services were already in place throughout the province, the parents found out about them by luck. Access to appropriate and timely services should be developed and improved.

The need for specialized support was also evident in the interview data. Irrespective of the severity of the hearing loss, all parents were shocked when they found out. Researchers are investigating the effects of the initial shock of the early diagnosis on the parent-child bond (Fitzpatrick et al., 2007; Yoshinaga-Itano, 2001; Young & Tattersall, 2007). The parents also emphasized the importance of access not only to genetic counselling and counsellors, but also to other parents who had gone through similar experiences. Edwards (2003) noted that most human beings "do not invite change into their lives" (p. 4). People function according to the pattern of their lives, and when something unexpected happens, most individuals resist that change. The parents in this study provided evidence of the individual ways in which parents react to the diagnosis. It is evident that the professionals' giving and the parents' receiving of the information were not always compatible. Different families have different coping styles, and professionals should strive to adapt their counselling styles and timing to each family's needs.

The parents also shared the challenges that they faced in dealing with the large numbers of professionals who became part of their lives after the screening. They lamented that they "didn't know what to do and where to go." Several researchers have noted a lack of collaboration in infant hearing programs (Bamford, Davis, Hind, McCracken, & Reeve, 2000; Bodner-Johnson, 2001; Corcoran, Stewart, Glynn, & Woodman, 2000; DesGeorges, 2003; Harrison & Roush, 1996; Luterman & Kurtzer-White, 1999; Russ et al., 2004; Sjoblad et al., 2001). A statement from one of the parents in this study commands our attention: "We need a professional to coordinate the professionals."

Conclusion

This study offers new insights from parents whose children went through NHS procedures, but who were not part of a comprehensive EHDI program. The parents' experiences were mixed, and they identified a number of areas for improvement. Some of the problems reported stemmed from the fact that the NHS was implemented without a comprehensive strategic plan for the management of congenital hearing loss. As province-wide guidelines for EHDI programs are being established, it is hoped that many of the issues reported by the parents should be resolved. However, no management program will ever be flawless and perfect.

Based on the stories of the parents in this study, one may be tempted to question the wisdom of implementing

screening without comprehensive planning. It is important to appreciate that despite the challenges and struggles, the parents were unanimously grateful for the early diagnosis of their child's hearing loss. The early diagnosis enabled them to take the necessary steps to assist their child.

The interview perspective employed in this study recognizes the parents' stories and opinions as their realities. They offer a snapshot of the challenges that many parents may face. They also highlight the need for professionals to try to understand the context in which they partner with parents to meet the needs of the child with a hearing loss. It is hoped that this study will inspire further research that will broaden our understanding of parents' experiences of the implementation of programs that involve NHS.

References

Alberta Universal Newborn Hearing Screening Project. (2000). *Universal Newborn Hearing Screening Program in Alberta: A pilot project: Protocols and guidelines.* Retrieved September 24, 2007, from http://www.babyhear.ucalgary.ca/Health_Professionals/UNHSProtocol.pdf

American Academy of Pediatrics. (1999). Newborn and Infant hearing loss: Detection and intervention. *Pediatrics, 103*, 527-530.

Bamford, J., Davis, A., Hind, S., McCracken, W., & Reeve, K. (2000). Evidence on very early service delivery: What parents want and don't always get. In R. C. Seewald (Ed.), *A sound foundation through early amplification: Proceedings of an international conference* (pp. 151-159). Stäfa, Switzerland: Phonak AG.

Barnard, S. (1997). *Qualitative data analysis: Content and thematic analysis* [PowerPoint presentation]. Retrieved February 20, 2005, from http://www.sohp.soton.ac.uk/moi301/thematic.htm

Benedict, B., & Raimondo, B. (2003). Family rights, legislation, and policies: What professionals need to know to promote family involvement and advocacy. In B. Bodner-Johnson & M. Sass-Leher (Eds.), *The young deaf or hard of hearing child: A family centered approach to early education* (pp. 61-95). Washington, DC: Paul Brookes.

Bodner-Johnson, B. (2001). Parents as adult learners in family centered early education. *American Annals of the Deaf, 146*(3), 263-270.

Brown, D., Dort, J., & Sauve, R. (2000). Newborn hearing screening programs: A truly Canadian perspective. *Journal of Speech-Language Pathology and Audiology, 24*, 48-53.

Canadian Working Group on Childhood Hearing. (2005) *Early Hearing and Communication Development: Canadian Working Group on Childhood Hearing* (CWGCH) Resource Document. Ottawa: Minister of Public Works and Government Services Canada.

Corcoran, J. A., & Stewart, M. (1998). Stories of stuttering: A qualitative analysis of interview narratives. *Journal of Fluency Disorders, 23*, 247-264.

Corcoran, J. A., Stewart, M., Glynn, M., & Woodman, D. (2000). Stories of parents and children with hearing loss: A qualitative analysis of interview narratives. In R. C. Seewald (Ed.), *A sound foundation through early amplification: Proceedings of an international conference* (pp. 167-174). Stäfa, Switzerland: Phonak AG.

Davis, T. C., Humiston, S. G., Arnold C. L., Bocchini, J. A., Jr., Kennen, E. M., Bocchini, A., et al. (2006). Recommendations for effective newborn screening communication: Results of focus groups with parents, providers, and experts. *Pediatrics, 117*(5, Suppl. 1), S326-S340.

DeSantis, L., & Ugarriza, D. N. (2000). The concept of theme as used in qualitative nursing research. *Western Journal of Nursing Research, 22*(3), 351-372.

DesGeorges, J. (2003). Family perceptions of early hearing, detection, and intervention systems: Listening to and learning from families. *Mental Retardation and Developmental Disabilities Research Reviews, 9*, 89-93.

Dort, J. (2000). **Universal Newborn Hearing Screening Program in Alberta** [Health Innovation Fund application]. Unpublished manuscript.

Durieux-Smith, A., Seewald, R., & Hyde, M. (2001). CASLPA-CAA position on universal newborn and infant hearing screening in Canada. *Journal of Speech-Language Pathology and Audiology, 24*, 139-141.

Durieux-Smith, A., & Stuart, A. (2000). Newborn hearing screening: A Canadian historical perspective. *Journal of Speech-Language Pathology and Audiology, 24*, 44-47.

Edwards, C. (2003). Reflections on counselling: Families and hearing loss. *Loud and Clear: A Cochlear Implant Rehabilitation Newsletter, 2*, 1-8.

Fitzpatrick, E., Graham, I., Durieux-Smith, A., Angus, D., & Coyle, D. (2007). Parents' perspective on the impact of the early diagnosis of childhood hearing loss. *International Journal of Audiology, 46*(2), 97-106.

Gallagher, P., Easterbrooks, S., & Malone, D. (2006). Universal newborn hearing screening and intervention: Assessing the current collaborative environment in service provision. *Infants and Young Children, 19*, 59-72.

Gracey, K. (2003). Current concepts in universal newborn hearing screening and early hearing detection and intervention programs. *Advances in Neonatal Care, 3*, 308 317.

Harrison, M., & Roush, J. (1996). Age of suspicion, identification, and intervention for infants and young children with hearing loss: A national study. *Ear and Hearing, 17*, 55-62.

Hergils, L., & Hergils, A. (2000). Universal neonatal hearing screening: Parental attitudes and concern. *British Journal of Audiology, 34*, 321-327.

Hyde, M. (2005). Newborn hearing screening programs: Overview. *Journal of Otolaryngology, 34*, S70-S78.

Hyde, M., & Riko, K. (2000). Design and evaluation issues in universal newborn hearing screening programs. *Journal of Speech-Language Pathology and Audiology, 24*, 102 118.

Joint Committee on Infant Hearing. (1994). Joint Committee on Infant Hearing 1994 position statement. *Pediatrics, 95*(1), 152-156

Joint Committee on Infant Hearing. (2000). Year 2000 position statement: Principles and guidelines for early hearing detection and intervention programs. *American Journal of Audiology, 9*, 9-29.

Luterman, D., & Kurtzer-White, E. (1999). Identifying hearing loss: Parents' needs. *American Journal of Audiology, 8*, 13-18.

Mazlan, R., Hickson, L., & Driscoll, C. (2006). Measuring parent satisfaction with a neonatal hearing screening program. *Journal of the American Academy of Audiology, 4*, 253-264.

McCracken, W. (2001). Educational placement. In R. G. Beattie (Ed.), *Ethics in deaf education: The first six years* (pp. 119-142). San Diego, CA: Academic Press.

Mehl, A., & Thompson, V. (1998). Newborn hearing screening: The great omission. *Pediatrics, 101*(1), 1-6.

Mencher, G., & DeVoe, S. (2001). Universal newborn screening: A dream realized or a nightmare in the making? *Scandinavian Audiology Supplement, 53*, 15-21.

Merriam, S. (1998). *Qualitative research and case study applications in education (2nd ed.)*. San Francisco: Jossey-Bass.

Merriam, S. (2002). *Qualitative research in practice: Examples for discussion and analysis*. San Francisco: Jossey-Bass.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook (2nd ed.)*. Thousand Oaks, CA: Sage

National Institute of Health. (1993). *Early identification of hearing impairment in infants and young children*. NIH Consensus Statement, 11, 1-24.

Northern, J., & Downs, M. P. (1991). *Hearing in children (4th ed.)*. Baltimore, MD: William & Wilkins.

Park, A. H., Warner, J., Sturgill, N., & Alder, S. C. (2006). A survey of parents' views regarding their child's hearing loss: A pilot study. *Otolaryngology Head Neck Surgery, 134*, 794-800.

Patton, M. (1990). *Qualitative evaluation and research methods (2nd ed.)*. Newbury Park, CA: Sage.

Patton, M. (2001). *Qualitative research and evaluation methods (3rd ed.)*. Newbury Park, CA: Sage.

Rubin, H. J., & Rubin, I. S. (2004). *Qualitative interviewing: The art of hearing data*. Newbury Park, CA: Sage.

Russ, S. A., Kuo, A. A., Poulakis, Z., Barker, M., Rickards, F., Saunders, K., et al. (2004). Qualitative analysis of parents' experience with early detection of hearing loss. *Archives of Disease in Childhood, 89*, 353-358.

Sjoblad, S., Harrison, M., Roush, J., & McWilliam, R. A. (2001). Parents' reactions and recommendations after diagnosis and hearing aid fitting. *American Journal of Audiology, 109*, 24-31.

Tattersall, H., & Young, A. (2006). Deaf children identified through newborn hearing screening: Parents' experiences of the diagnostic process. *Child Care Health Development, 32*(1), 33-45.

Vaccari, C., & Marschark, M. (1997). Communication between parents and deaf children: Implications for socio-emotional development. *Journal of Child Psychology, 38*, 793 801.

Weichbold, V., Welzl-Mueller, K., & Mussbacher, E. (2001). The impact of information on maternal attitudes towards universal neonatal hearing screening. *British Journal of Audiology, 35*, 59-99.

Widen, J., Bull, R. W., & Folsom, R. C. (2003). Newborn hearing screening: What it means for providers of early intervention services. *Infants and Young Children, 16*, 249 257.

Yoshinaga-Itano, C. (2001). The social-emotional ramifications of universal newborn hearing screening, early identification and intervention of children who are deaf and hard of hearing. In R.C.Seewald and J. Gravel (eds.), *A sound foundation through early amplification: Proceedings of the second international conference,* (p. 221-231). Switzerland; Phonak, AG.

Young, A., & Tattersall, H. (2007). Universal newborn hearing screening and early identification of deafness: Parents' responses to knowing early and their expectations of child communication development. *Journal of Deaf Studies and Deaf Education, 12*(2), 209 220.

Author Note

Sarah Kelly is now at the Department of Educational Administration, Foundations and Psychology, University of Manitoba, Winnipeg, Manitoba.

Correspondence concerning this article should be addressed to Sarah Kelly, Faculty of Education, University of Manitoba, Winnipeg, Manitoba R3T 2N2
E-mail: sarah_kelly@shaw.ca

Received: December 19, 2006

Accepted: January 30, 2008