Parents’ Needs Following Identification of Childhood Hearing Loss

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Purpose: Appropriate support for families of children diagnosed with hearing impairment may have a direct impact on the success of early hearing detection and intervention programs in reducing the negative effects of permanent hearing loss. We conducted a qualitative study to explore parents’ needs after learning of their child’s hearing loss to better understand the important components of service delivery from families’ perspectives.

Method: Semistructured interviews were conducted with 17 families (21 parents) of preschool children in 4 centers in Ontario, Canada. Parents of children identified by neonatal screening as well as those identified through traditional referral routes participated. We asked parents to share their perceptions of the strengths and gaps in the care system.

Results: Although the majority of parents were satisfied with the range and quality of audiology and therapy services available, they identified gaps in the areas of service coordination, availability of information, and the integration of social service and parent support into the system. Access to audiology services appears to have been facilitated for children who were systematically screened.

Conclusions: The findings provide insights into the services most valued by families. These findings highlight the importance of eliciting parents’ perspectives in designing optimal care models for children and families.

Key Words: family-friendly, hearing services, family-centered, early intervention, early detection

Universal newborn hearing screening (UNHS) has attracted worldwide attention as a public policy intervention aimed at improving outcomes for children with hearing loss and their families. Population-based newborn hearing screening gained momentum as an intervention in the 1990s due to new and efficient screening technologies and the realization that high-risk screening initiatives effectively identified only 40%–50% of infants with hearing loss (Davis et al., 1997; Durieux-Smith & Whittingham, 2000). Studies supporting the benefits of UNHS in improving communication development garnered interest in establishing UNHS as part of comprehensive early hearing detection and intervention (EHDI) programs (Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998).

The concept of screening of disease is endorsed by the World Health Organization when an effective treatment program is available (Strong, Wald, Miller, & Alwan, 2005). In the field of infant hearing, the Joint Committee on Infant Hearing (2000) has recommended the early identification and management of childhood hearing loss through universal screening. It is well recognized that UNHS constitutes the first step in a comprehensive system of care aimed at...
preventing or reducing the negative consequences of childhood hearing loss. Early detection must be followed by intervention including technology and rehabilitation to enable the child to participate in society. In view of the prevalence of UNHS initiatives and in recognition of the lack of documented best practices for infant hearing services, a consensus panel was convened in 2001 to develop a position statement regarding management principles and to discuss state-of-the-art practices for infants with hearing loss (Jerger, Roeser, & Tobey, 2001). The panel recommended that newborn hearing screening be embedded in a system of comprehensive services for infants that would include the identification of hearing loss, family guidance, selection and fitting of technology, management, and counseling. Recently, the Canadian Working Group on Childhood Hearing also recommended that the management of childhood hearing loss be addressed in a comprehensive, family-oriented service delivery model (Canadian Working Group on Childhood Hearing, 2005).

Despite these efforts and the recognition that broad care models are desirable, several researchers have raised concerns about follow-up services to UNHS. Recent reports have indicated that although UNHS can be effective as a path to intervention, the capacity of population-based screening to improve longer-term development outcomes is uncertain (Centers for Disease Control and Prevention, 2003; Vohr, Moore, & Tucker, 2002; White, 2003). Historically, services for the management of pediatric hearing loss have evolved in a piecemeal fashion with responsibilities assumed by various agencies, such as health, education, and social services. Many existing treatment or intervention services evolved prior to the current focus on UNHS, the availability of current hearing technology, and the emphasis on evidence-based practice. Research undertaken in the United Kingdom in preparation for a new UNHS program revealed several barriers to the implementation of UNHS both from professionals’ and parents’ perspectives (Bamford et al., 2001; Robinshaw & Evans, 2003). In the United States, the referral of families for early intervention has been described as the weakest link in the EHDI system (Sass-Lehrer, 2004).

Family-centered care is advocated as an important characteristic of best practices for infant hearing health services from the identification through the intervention process (Gravel & McCaughey, 2004; Harrison & Roush, 2004; Robinshaw & Evans, 2003). It has been proposed that an intervention approach that values partnerships with families and promotes self-efficacy in parents may result in higher rates of follow-through, greater participation in early intervention, and improved outcomes for children with hearing loss (Sass-Lehrer, 2004). The importance of family involvement was found in one study to be an important predictor of communication outcome in children by 5 years of age (Moeller, 2000). Process variables such as quality of relationships between professional and parents and parents’ sense of efficacy have been identified as potential key factors in achieving positive outcomes (Calderon, 2000; Eriksson-Brophy et al., 2006).

Likewise in Canada, as the country embarks on population-based newborn hearing screening, the notion of family-centered care also prevails (Hyde, 2005). In the province of Ontario, where a universal infant hearing and communication development program was implemented in 2002, a major goal is to “provide parents of deaf or hard of hearing infants with the services their children need in order to develop communication and language skills, and to give them the best start in life” (Government of Ontario, 2006). Key components of the Ontario infant hearing program include universal screening, standard evidence-based audiologic assessment, psychosocial support, and unbiased information from a family support worker (Brown & Mackenzie, 2005; Hyde, Friedberg, Price, & Weber, 2004). A range of communication development options from auditory-verbal to manual-based approaches are provided for families.

Aligning services with parents’ expectations and preferences may be an important determinant of outcome in early intervention services. Despite the recent attention accorded to UNHS, relatively little emphasis has been placed on parents’ views of their needs after the detection of hearing loss and the service models needed to address them. Attributes of service models such as parental involvement in intervention and quality of therapy may be critical factors in determining the effectiveness of an intervention program (Yoshinaga-Itano, 2004). With a newly implemented UNHS program in the province of Ontario, this study was undertaken to better understand, from the perspective of parents of young children with hearing loss, the supports required to give their children the best start in life. The data reported here are from a study designed to learn about parents’ perspectives on the benefits of early hearing detection as well as their needs after learning of a hearing disorder. The results of the first objective have been recently reported (Fitzpatrick, Graham, Durieux-Smith, Angus, & Coyle, 2007), and the latter objective forms the basis of this article. Specifically, the study sought to (a) identify parents’ needs during their experience in caring for a young child with hearing loss through the spectrum of care from identification to fitting of amplification to rehabilitation, (b) identify the strengths and gaps in the system of care experienced by the families, and (c) outline the important attributes of childhood hearing services from the perspective of families.

Method

This study adopted qualitative methods to address the research question in order to better explore an area less amenable to quantitative research methods (Pope, 1995). The use of qualitative research and mixed methods (quantitative and qualitative methods combined in one study), commonly employed in social science research, has gained increasing acceptance in health research. This is in part due to a growing recognition of the complex nature of many health interventions and evaluations (Moffatt, White, Mackintosh, & Howell, 2006; Pope & Mays, 2000). Although qualitative research does not permit statistical inferences to be made, there is a growing interest in the contribution of rigorous qualitative methods to the identification of study variables, the development of measurement tools (e.g., health research surveys), the examination of aspects beyond traditional outcomes, and the understanding of findings from quantitative studies (Barbour, 2001; Moffatt et al., 2006; Pope & Mays, 2000). The ultimate goal of qualitative research is to provide an accurate picture of reality as viewed through the lens of the participants (Creswell, 1998). In this study, qualitative
research was undertaken to illuminate families’ needs for support from the perspective of those individuals most affected by childhood hearing loss.

This study applied qualitative research techniques in the form of semistructured interviews to examine parents’ needs following diagnosis of a child’s hearing loss. In adopting a qualitative research approach, we sought an identification of the elements of care that parents considered most important rather than setting a priori expectations. In addition to providing insights into parents’ perspectives, the data from the study were intended to inform further quantitative examination of the important attributes of service models (Fitzpatrick, Coyle, et al., 2007).

**Participants**

Parents from four intervention programs in three cities in the province of Ontario, Canada, were invited to participate. Audiology services were provided through hospital and university clinics, and therapy was provided in a variety of settings, including hospital clinics and community and home-based settings. The majority of participants were selected from a sample of 65 parents who were enrolled in a multicenter longitudinal study investigating the benefits of systematic screening for children with permanent hearing loss (Fitzpatrick, Graham, et al., 2007). Families of children under age 5 with early onset permanent hearing loss (before 6 months of age) who were enrolled in oral communication development programs met the study inclusion criteria. Consistent with the larger study population, children with additional disabilities were also excluded from the qualitative inquiry. The study included only children enrolled in oral programs, as the large majority (estimated 90%) of families in Ontario are enrolled in oral communication programs (Ontario Ministry of Health, personal communication, May 16, 2006), and it is quite possible that there are differences in the needs of families enrolled in various communication development options (e.g., individual therapy sessions vs. group teaching settings). The project was approved by all four institutional review boards, and written informed consent was obtained from all participants.

For the qualitative research study, we purposefully constructed a maximum variation sample of 17 families to reflect a range of child and family characteristics that could influence parents’ views on services. In selecting the sample, variability was sought in regard to identification (systematic screening or traditional referral practices), severity of child’s hearing loss, type of hearing device, distance to therapy program, and parental education. Consistent with qualitative research, the emerging analysis guided the number of participants interviewed, and recruitment was discontinued when data saturation was reached; that is, no new themes were apparent in the interview data.

**Procedure**

We conducted individual in-person interviews using a semistructured interview guide. The questions related to parents’ perceptions of their needs after identification and the primary components of a service model for children with hearing loss and their families. Participants were also asked for their vision of a service model if they were redesigning the health care package for families and children with hearing loss. The two main questions were: (a) What were your needs following diagnosis of your child’s hearing loss? (b) If you could redesign the system, what would be the important components of a model? The participants were encouraged to think about the strengths and gaps in the existing services to assist them in formulating their ideas. As the interviews progressed and data were analyzed, questions were added to elucidate parents’ views on topics from previous interviews, particularly with respect to service coordination and a team approach to care.

Data collection was conducted over a period of 4 months, with all interviews conducted by the same interviewer. The interviewer was a researcher with a background in audiology/therapy and several years’ experience as a clinician/program manager in audiology services. All but one interview took place in the families’ home environment. The parents were encouraged to share their perspectives according to their level of comfort and to focus on issues of importance to them based on their experiences in caring for their child. They were encouraged to support their responses with examples from their personal experiences. All interviews were audio-taped and transcribed verbatim shortly after each meeting with one exception due to a technical equipment problem; the content of this interview was immediately summarized in an audio-recording by the interviewer.

Seventeen interview transcripts supplemented by interviewer notes and memos provided the data set for analysis. Data collection and analyses proceeded in an iterative manner with new data guiding and confirming the developing analysis and guiding future interviews. The data were analyzed by the interviewer using the software package Atlas-ti and adopting techniques described by Strauss and Corbin (1998). Each line of the interview was carefully read and scrutinized to identify key concepts that were compared across interview scripts. Initial coding was broad, and similarly coded data were then grouped into categories. Memos were written throughout the coding process to summarize the reflections and interpretations of the data as the analysis proceeded. Data collection was discontinued when incoming data did not appear to generate new insights. A second reviewer with expertise in pediatric hearing loss independently reviewed the data to verify the categories/concepts identified. These categories were collapsed into themes to synthesize parents’ views.

**Results**

Demographic information was collected from the participants to better understand family characteristics and potential factors that might influence their views. This information was collected to provide more detailed contextual information that can assist with data interpretation in qualitative research. The small sample size and nature of qualitative research precluded a statistical analysis of factors that predict families’ views on service needs. The key demographic and clinical characteristics of the children and families are detailed in Table 1.
Table 1. Characteristics of participants (n = 17).

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>% (or range)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Screening status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Screened</td>
<td>7</td>
<td>41.2</td>
</tr>
<tr>
<td>Not screened</td>
<td>10</td>
<td>58.8</td>
</tr>
<tr>
<td><strong>Age at diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Before 12 months</td>
<td>9</td>
<td>52.9</td>
</tr>
<tr>
<td>After 12 months</td>
<td>8</td>
<td>47.1</td>
</tr>
<tr>
<td><strong>Region (residence)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>15</td>
<td>88.2</td>
</tr>
<tr>
<td>Rural</td>
<td>2</td>
<td>11.8</td>
</tr>
<tr>
<td><strong>Parental education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean years&lt;sup&gt;a&lt;/sup&gt;</td>
<td>16.9</td>
<td>Range = 13–23 years</td>
</tr>
<tr>
<td>Trade school (13–16 years)</td>
<td>5</td>
<td>29.4</td>
</tr>
<tr>
<td>University (≥17 years)</td>
<td>12</td>
<td>70.6</td>
</tr>
<tr>
<td><strong>Degree of hearing loss</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>1</td>
<td>5.9</td>
</tr>
<tr>
<td>Moderate</td>
<td>5</td>
<td>29.4</td>
</tr>
<tr>
<td>Severe</td>
<td>6</td>
<td>35.3</td>
</tr>
<tr>
<td>Profound</td>
<td>5</td>
<td>29.4</td>
</tr>
<tr>
<td><strong>Device type</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hearing aids</td>
<td>10</td>
<td>58.8</td>
</tr>
<tr>
<td>Cochlear implants</td>
<td>7</td>
<td>41.2</td>
</tr>
<tr>
<td><strong>Rehabilitation program&lt;sup&gt;b&lt;/sup&gt;</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Auditory-verbal</td>
<td>14</td>
<td>82.4</td>
</tr>
<tr>
<td>Oral</td>
<td>3</td>
<td>17.6</td>
</tr>
<tr>
<td><strong>Location of therapy</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinic setting</td>
<td>12</td>
<td>70.6</td>
</tr>
<tr>
<td>Home</td>
<td>2</td>
<td>11.8</td>
</tr>
<tr>
<td>Clinic/home combination</td>
<td>3</td>
<td>17.6</td>
</tr>
</tbody>
</table>

<sup>a</sup>Defined as the highest number of years of education for one parent.

<sup>b</sup>As identified by parents.

At their discretion, parents participated in the interviews individually or with a significant other person. All were hearing parents, and the 17 interviews involved a total of 21 individuals, with participation as follows: 10 mothers alone, 1 grandmother (the child’s main caregiver), 2 fathers, and 4 mothers and fathers together. Two of the families also had a second child with a hearing loss. Fifteen of the 17 families lived in an urban center. The majority of parents (11 of 17) had experienced the diagnostic process for a period of less than 3 years (range = 11–44 months) prior to participating in the interviews. All interviews were conducted in English.

Seven babies had undergone a systematic hearing screening procedure (5 universal screening, 2 high-risk screening), and 10 had been referred for hearing assessments through traditional referral routes, typically through the family doctor, because of parent suspicion of a problem. The average age of diagnosis of all children in the sample was 16.1 months (range = 0.8–41.9 months). Nine children were diagnosed before 12 months of age, including 6 who had undergone systematic hearing screening. The sample was selected to include children with varying degrees of hearing loss and different hearing devices. The sample included more children with severe and profound degrees of hearing loss consistent with participation in the larger study from which the majority of families were recruited. Severity of hearing loss was distributed as follows: 1 child with mild, 5 with moderate, 6 with severe, and 5 with profound hearing losses. Ten children used hearing aids, and 7 had received cochlear implants at the time of the interview. All 17 parents reported having post-secondary education. Fourteen of these 17 families, who had selected an oral communication rehabilitation approach, were enrolled in auditory-verbal therapy, reflecting the primary rehabilitation choice for families in the province of Ontario.

**Parents’ Views on Needs and Service Provision**

The profound effect of a childhood hearing loss on the family was captured in the experiences and decisions made by parents in the early stages. As illustrated in 2 mothers’ words below, parents described the disorder as a phenomenon that not only affects the child but changes their lives and affects such family decisions as career, finances, and place of residence:

So, I think the impact has been a bit deflating to his childhood. And, of course, the stress to us, it’s changed everything about our decisions, about how he’s going to be educated, about whether I’m going back to work or not. Everything has been impacted. (Interview 7)

Once you make the decision, you want to know where your future lies. Like we quit our jobs and changed our lives and came to Canada for him. (Interview 10)

Since permanent childhood hearing loss is a lifelong condition for the child, it brings with it long-term requirements for family support in a number of areas. The views related to needs and service provision that emerged from the data were summarized into four key discussion themes: (a) components of service model, (b) coordinated care, (c) parent contact, and (d) information needs. Although these themes were frequently overlapping and interrelated, they have been separated to facilitate the synthesis of the data and are elaborated in the following sections. The major themes and subthemes, as well as the number of parents reporting them, are outlined in Table 2 and described with illustrative quotes in the text below.

**Components of Service**

**Screening.** All parents expressed the view that newborn hearing screening services should be an important part of the overall service delivery model for children with hearing loss. A discussion of screening as a part of the service needs was not a focus of these open-ended interviews, which targeted parents’ views on their needs following identification of their child’s hearing impairment. However, throughout the interviews, several families of children who did not have access to screening and who experienced later diagnosis of hearing loss expressed strong opinions about the importance of maintaining newborn hearing screening in the overall package of public health services (Fitzpatrick, Graham, et al., 2007).

**Intervention.** Audiology and therapy services were unanimously identified as vital components of the service model for children with hearing disorders regardless of the severity of hearing loss. A few parents expressed some dissatisfaction...
regarding timely access to pediatric audiology services during the initial identification stage; this appeared to apply to children diagnosed prior to the implementation of the universal screening program and has been elaborated in a previous report (Fitzpatrick, Graham, et al., 2007) as a potential benefit of infant hearing screening initiatives. For some parents, consistent with recent reports, there was dissatisfaction around communication of the diagnosis that appeared to emanate from the manner in which the news was delivered (Young & Tattersall, 2005). It is important to note that these families came from a variety of clinics and were identified with and without exposure to screening. Those who experienced universal screening services were diagnosed during the first year or two of the implementation of the new services, possibly before all of the features of the new program had been well integrated into the system of care.

Once parents progressed beyond the initial difficult stages, and the intervention program including amplification and therapy was established, the overwhelming majority described a high degree of satisfaction with the audiology and therapy services provided. Parents in this study were enrolled in family-oriented services focused on oral communication development (14 auditory-verbal and 3 oral) at community, hospital, or home-based clinics. All received clinical or home-based therapy services, where a therapist guided the parent on language stimulation during individualized child/parent rehabilitation sessions, a hallmark of auditory-verbal therapy (Estabrooks, 2006). Distance to service was a concern for some parents, particularly those from rural or large metropolitan areas who were required to travel to a clinic for some or all services. Six of the 17 families reported commuting time of 45 min or more to reach the clinical therapy program. It is also noteworthy that a few parents of children who used hearing aids expressed the view that the focus on cochlear implants in hospital clinics led to a perception that their child’s less severe hearing loss was somehow less important.

Notwithstanding these concerns, overall, parents spoke of being fortunate to live in a city or country with high-quality services that effectively guided them in developing their child’s oral communication skills. Throughout the interviews, parents talked frequently and positively about the therapy. In particular, all of the parents talked about the value they placed on the emotional support and specific coaching in language development provided through the continuing contact with the therapist. The relationship and guidance from the therapist through consistent weekly therapy sessions emerged as one of the most fundamental characteristics of services for families. In addition, communication between the audiology and therapy services and shared objectives were described as key attributes of a good quality service:

I’d have to say … the services that we have had, have been remarkable, audiology and audio- verbal therapy, so really [there is] very little to change. And so 3½ years into this therapy, she looks forward to going … and … I attribute that very much to the quality of the service there and how they keep these sessions entertaining. (Interview 4)

Other service components. In addition to audiology and therapy, parents talked most frequently about social work services; however, this was usually described as ancillary to the intervention services of audiology and rehabilitation. The majority of parents appeared to have had contact with a social support worker upon learning of the hearing loss or shortly afterward. Few parents spoke of having had exposure to psychology services except those considered for cochlear implantation, and it appeared to be viewed as a discrete, one-time developmental assessment for cochlear implantation with no expectation or apparent need for follow-up. For the parents whose children had been screened, all appeared to have encountered social support services as part of the provincial infant hearing program. For the others, it seemed to vary depending on the clinic at which the hearing loss had been identified. There was great variability in parents’ experiences and views on the need and value of social service supports, generally provided by social workers or family support workers. For some parents, the initial encounters with social support appeared to be confusing, as the service was separate from the audiology and/or therapy program. Parents did not present a consistent view of the role of the family or social support worker and how the individual was integrated into the process of care. A few parents felt that the social worker did not have sufficient technical or medical information about hearing loss and its consequences to provide needed counseling in the early stage. Others spoke very highly of the need for such a service in helping to navigate and access the myriad of services and financial support available. The reflections of 2 parents who were provided with social support shortly after the diagnosis illustrate the wide variability in parents’ experiences and perceptions on the need and value for this service:

I think everyone needs that support worker, she was phenomenal, without her, I wouldn’t know what to do…. She was the one who set us up with speech-language pathology and everybody. Once we got the support worker, everything happened quickly, yeah. Yeah, we

Table 2. Families’ perspectives of needs following diagnosis of hearing loss.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Components of service (17)</td>
<td>Screening (17)</td>
</tr>
<tr>
<td></td>
<td>Audiology (17)</td>
</tr>
<tr>
<td></td>
<td>Therapy (17)</td>
</tr>
<tr>
<td></td>
<td>Social support (15)</td>
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<tr>
<td></td>
<td>Funding support (6)</td>
</tr>
<tr>
<td>Coordinated service (15)</td>
<td>Colocated services (9)</td>
</tr>
<tr>
<td></td>
<td>Team coordination (13)</td>
</tr>
<tr>
<td>Support from parents (16)</td>
<td>Organized through health (5)</td>
</tr>
<tr>
<td></td>
<td>Through parents’ groups (11)</td>
</tr>
<tr>
<td>Information (17)</td>
<td>Hearing-specific (11)</td>
</tr>
<tr>
<td></td>
<td>Therapy/resource options (9)</td>
</tr>
<tr>
<td></td>
<td>Prognostic guidance (12)</td>
</tr>
<tr>
<td></td>
<td>Access to information (8)</td>
</tr>
</tbody>
</table>

Note. Values in parentheses represent the number of families (of the total 17 families) coded as identifying these topics during the interviews.
were trying to get everything, so I definitely think families should be hooked up with a support worker. (Interview 17)

We saw her [parent support worker], and she gave us a huge binder with many dividers. Ultimately, I had a list of providers for auditory-verbal therapy, a list of providers for sign language, a list of providers for total communication options, and other than that it was empty and not very useful…. And I guess the referral system worked but then I was finding that either they weren’t getting the information from her fast enough, or fast enough in my mind … it wasn’t feeling like a lot of support was coming from there anymore. (Interview 14)

Other services that were not typically viewed as part of hearing health services were described as difficult to access (e.g., developmental pediatrician), and some parents pointed out that the overall developmental needs of the child with hearing loss should be considered. Another gap in care related primarily to funding to support equipment purchases (e.g., part of the initial cost of the hearing aid as well as hearing aid/cochlear implant batteries, replacement parts and repairs), therapy travel costs (e.g., fuel, parking), and other costs (e.g., child care and time away from work). Parents commented that these practical but essential aspects of care presented a barrier to optimal service and had not received sufficient attention at a policy level.

It’s the typical middle class syndrome where we are still paying for services that I think should be free, only because this is something she needs to function on a daily basis. (Interview 3)

**Coordinated Service**

Access to coordinated care was an important theme that emerged early in data collection and warranted further inquiry during subsequent interviews. The above quotes exemplify the frustration of parents when they perceive a system composed of individual components where structural and operational issues present barriers. When services were viewed as fragmented, this appeared to affect, in particular, the process from diagnosis to intervention. Although not frequent, this breakdown was perceived by families who experienced the diagnosis with and without systematic screening. Their experiences suggested that a clear picture of the care pathway was missing, and they were left without support until they accessed the therapy service. Parents who had less desirable experiences during the early stages appeared to be more mistrusting of providers. During the interviews, these parents reflected back to their initial experience, which appeared to act as a catalyst for their views on current care practices:

I would really like to deal with one organization…. I wish I could deal with one organization, rather than two, or at least having these two on a good path. I wish, you know, whatever organizations are out there, they need to be working together. I wish there was a consensus of what people with hearing losses need because we want as many avenues for our child as possible. (Interview 17)

What I would like to see is that you get to have a meeting with the ENT, the audiologist, and an auditory-verbal therapist and a social worker … with everybody together in one room saying, “Here’s where our goals are right now for your child, and here are the kinds of tests we’re going to run in order to determine what her future needs might be and this is what the process looks like”—a flow chart if you will. (Interview 7)

The notion of coordinated team services did not have the same meaning for all parents, as illustrated by the quotes below. For some, it appeared to be related to the colocation of the various health providers, but to others, coordinated care depended on the communication and the shared vision of the providers most involved in the child’s care. Parents’ endorsement of different models of service provision appeared to be based on their positive experiences with a model. In some cases, it likely reflected the reality of living in an urban or large metropolitan area at considerable distance from the child’s audiology center. Some parents described audiology and therapy services that worked together effectively whether or not they were colocated, while in other cases, audiology and therapy were described as two distinct programs. For some families, there was a perception that one team member, usually a therapist who adopted a coordinator role, created a successful “virtual” team. The therapist, with whom parents typically interacted on a weekly basis, was an important link with other team professionals:

We can see our ENT, our auditory-verbal therapist, our audiologist, and the cochlear implant specialist all in one spot. We don’t need to go whipping around all over the place and go to different spots. Where in other places … it’s very fragmented … here, we’re very fortunate, it’s all in one spot, and they all share information. (Interview 3)

It [the model] works very perfectly because everything just seems to gel together because … you go to the audiologist, the speech therapist, the family doctor, the school, itinerant teacher, they have a different approach, but the content and the objectives are the same…. The therapist is very involved with him, she would normally call around to find out what’s happening…. Everybody is kept on pace as to what is happening. She’s [therapist] probably the unofficial case manager. (Interview 9)

… because we get to see the therapist most often so they know us, they can see the progress or problems. I still think the therapist is a window to see what’s going on for other people in the team. We can’t get to see the audiologist without an appointment, but I just thought if the therapist … relays the problems or parents’ concerns to the audiologist more, and doctors more, that would be helpful. (Interview 1)

**Support From Other Parents**

Parent contact was acknowledged by all families as a useful adjunct to the services provided through typical health care channels. Families who strongly embraced parent support suggested that it should be an integral part of the
health care system. They felt that current practice models
offered this support in an ad hoc manner, leaving it as the sole
responsibility of a volunteer parents’ group. Parent support
groups or access to parental input seemed to fulfill several needs,
including knowledge sharing, practical information about
hearing devices and community resources, prognostic infor-
mation, and hope. For some parents, it also filled an emotional
support need beyond what could be offered by psychoсо-
al providers in health care. A few parents commented that it
supported healthy development of their child as children saw
peers with the same type of communication disorder:
And sometimes parents trust other families better than they
trust professionals or understand them better, and I think,
yes, because in the long-term it impacts a parent’s decision
making for their child’s services and that will impact the
child’s outcomes as well. (Interview 7)
I guess one of the things that we wanted that you really
want right from the beginning is you want to speak to
parents that have had children implanted and get their
feedback on what they think it’s done for their child. And
at the same time, we wanted to speak to adult users because
children can’t tell you what the hearing is. (Interview 4)

Information Needs

The requirement for information was a subject that filtered
through several aspects of the discussion. From the interview
data, parents’ information requests could be classified into
several domains: (a) hearing loss-specific information (e.g.,
etiology, severity of loss, hearing aid and cochlear implant
technology), (b) therapy-related information including
therapy options and other resources in the community, and
(c) prognosis information.

Hearing loss-specific information. The majority of par-
ents reported satisfaction with the medical and technical as-
psects of hearing loss received through their clinics. Parents
referred to a strong need for information at the beginning of
the diagnosis and a need for ongoing, up-to-date information
throughout the continuum of care, particularly in the technol-
domy domain (e.g., bilateral cochlear implantation). There
were no obvious differences in parents’ views across the spec-
trum of hearing loss or route to identification of hearing
loss. Families of children with mild to moderate hearing
losses talked about the importance of information as much as
parents of children with profound hearing impairments.
There were also no perceptible differences in the information
needs identified by parents of children who were diagnosed
with hearing impairment in the presence or absence of sys-
tematic screening programs.

I will say it’s overwhelming in the beginning … you want
the information, however, at the same time you’re trying
to take in so much information that it is a lot to take in.
But they did provide us with all sorts of literature, videos,
support through our auditory-verbal therapist, through the
audiologist, regular appointments to keep us in contact.
(Interview 3)

Therapy and resource options. The large majority of par-
ents expressed that information on various therapy options
had been adequately presented either by the clinic audiologist/
therapist or a social support worker. However, several families
felt they were left without adequate support in locating var-
ious resources. Access to information on options for resources
in the community such as home tutoring and additional sup-
port through the educational system was, however, less
positively viewed.

The [program] was very diplomatic in giving us informa-
tion. I sort of figured out what was going on after the
fact, but I appreciated how they did it. They never said this
is what you should do … they sort of kept always making
sure we were aware of things. (Interview 13)

Like I said, first there was a lot of figuring things out, so it
would be nice to have somebody so that you know everything
that’s available, that way you can start figuring out
what you need for your child. (Interview 6)

For parents to share information and tips … we’ve got lots
of tips on equipment, even for things like income tax pur-
poses. We found out about a tutor service through the
parent group, we didn’t know about it. So I just think some
of these steps maybe need to be in place. (Interview 3)

I asked the clinic [about other services] because I did want
something for the other week because I found that therapy
kind of reenergized me, sort of focused me…. So that’s
when my AV therapist brought up [other program] and
home visits, so that was the only way I found out about
that, and I was a little miffed … because it was never
brought to my attention. (Interview 11)

Information on child’s prognosis for oral communication
development. In the early stages of learning about the hear-
ing loss, information about the child’s prognosis was often
lacking. The importance of this was described by one parent
as follows:

I guess we wanted to know what his loss would translate
into, so we knew he had a loss, and we knew the severity
of the loss … we had all the details, but what we really
wanted to know is what does this really mean…. Does it
mean that he’ll grow up having to learn sign, or will he
be able to just use language, spoken language, regular
classroom placement? (Interview 6)

The following extracts from interviews reveal some of the
many ways parents expressed this desire for additional in-
formation on their child’s potential to develop spoken com-
munication. Essentially, parents wanted the best available
evidence supporting intervention outcomes:

You have to see the success, maybe that’s what I’ll high-
light to you…. So my husband was reading about how
high the unemployment rate was for people who are deaf
and some of the other negatives and the stigma attached
to that, so we needed to kind of see the other side to know
that there was hope. (Interview 4)

Not that we want to be, like comparing, but you want to see
where he should be at … even though we know there are
so many things involved…. We were searching the Internet
to find stories of kids being implanted because we were trying
to get him implanted as early as possible. (Interview 10)
One of the other things we found just kind of somewhat lacking is, like, some of the research results, for example … most kids in this range tend to learn these sounds of these types of words by this age … they have that for normal kids. (Interview 10)

*Parents’ views on access to information.* Information sources included health care/education providers; printed materials such as brochures, books, and journals; media such as videotapes of children; the Internet; and personal communication primarily with other families of children with hearing loss. While parents generally felt that their health and education providers were well informed and willing to share information, they offered concrete suggestions on how the health service could ensure that information both on programs and technical-medical aspects is available in an on-going, up-to-date way. Several parents suggested a resource room at the diagnostic or rehabilitation center where families could find multimedia sources including videos, books, articles, and Internet resources. Another practical suggestion was for the agency to provide a list of recommended Internet sites.

I’d almost have a kit, maybe literature, up-to-date literature with books and videos, not too, too much, but to have some things there for the beginning so that families don’t need to find it … it’s right there for them when they need it and they want it. So that’s a huge thing. I think that I would ask, only because we felt we were kind of running for everything we needed, and maybe knowledge is power. (Interview 3)

Parents described a certain comfort in being able to consult multiple sources for information including professionals, books and journals, videos, and the Internet. The Internet emerged as a prominent source of information for parents, both for locating resources (e.g., clinic programs, parent support groups) and up-to-date technical information. A parent with a child identified prior to the implementation of universal screening described how she used the Internet to locate a rehabilitation service. Others described using the Internet as a resource for lesson plans and a link to various professionals to obtain different perspectives on therapy options. Parents of children with cochlear implants described manufacturers’ Web sites and online discussion groups as a valuable source of information. Some parents judged that the Internet was not sufficiently exploited as a resource by the health system.

We got back up to the cottage [after the diagnosis], and so we logged onto the Internet and just started reading. And we went to the [program] Web site, I think that’s where we got the most amount of information, read the testimonials from the parents…. we phoned them and talked to them about it, and that was our first link. Now, I know of all of these other services and programs, but that was my link. (Interview 13)

**Discussion**

Population-based newborn hearing screening presents new opportunities for children with hearing loss and their families. However, there is a realization that the success of newborn screening is largely dependent on the implementation of adequate support programs for children and families (Hyde, 2005; White, 2003; Yoshinaga-Itano, 2004). Using a qualitative research approach, this study identified parents’ views on service needs for childhood hearing loss. The study was undertaken shortly after the implementation of a newly established universal screening program in Ontario, Canada. While the new program provided the context and motivation for the present study, recruitment for these parent interviews was initiated shortly after the introduction of the new infant hearing program in Ontario (Hyde et al., 2004). Therefore, the necessary inclusion of families of children who had been diagnosed in a variety of contexts may not reflect the situation since the full implementation of province-wide universal hearing screening and communication development services. However, the primary purpose of this qualitative research was to elicit parents’ views on their needs following diagnosis of a child’s hearing loss, and several broad conclusions were extracted from the 17 family interviews. In general, parents valued quality audiology and therapy services as core support services. While the amount and location of therapy programs were problematic for some families, the majority were very satisfied with the guidance and professional caliber of these services. In addition to these core services, families identified a variety of other desirable supports from the publicly funded care system, including social service support, financial support for devices and travel, and contact with other parents who had experienced the process of hearing loss. Two systemic problems appeared to affect the process of receiving appropriate support for some families in the early stages of diagnosis: (a) knowledge of and access to the various services/resources that were available and (b) the lack of coordination within clinics and between various clinic providers and agencies. With time, parents seemed to learn how to navigate the system and were generally very satisfied with the ongoing services that were provided.

The finding that parents seek hearing-specific medical and technology details as well as intervention-related information is consistent with previous research (Des Georges, 2003; Luterman & Kurtzer-White, 1999; Robinshaw & Evans, 2003). An additional important finding of our research that has received cursory attention in the literature was the desire of many parents to have some notion of the prognosis for their child with a specific hearing loss and the sense that this information was lacking. While this need has been mentioned in previous studies (Kurtzer-White & Luterman, 2003; Neuss, 2006), it was a particularly noticeable theme in this study and may reflect the perceptions of educated and informed consumers. It is unclear from the literature whether this information is not provided because clinicians are unaware that parents desire such information, are uncomfortable discussing prognostic information, or simply do not have evidence-based prognostic indicators.

While parents generally felt that the providers they encountered were highly knowledgeable about hearing loss, they also commented that they would like to receive professional guidance in seeking information beyond that offered by clinic providers. The Internet emerged as an important access point for parents; however, several families expressed...
that this source was not sufficiently supported and maximized by providers in health services. The finding that parents rely heavily on the Internet for information emphasizes the shift in how patients seek information as described by other health researchers (Hardyman, Hardy, Brodie, & Stephens, 2006). The benefits of receiving timely and ongoing information were described as increased involvement in and more informed decision making, for example, regarding cochlear implantation, and greater satisfaction with services provided. In other areas of health such as cancer care, information seeking has been demonstrated to play a critical role in individuals’ efforts to cope with the negative impacts on quality of life associated with a disorder (Rutten, Arora, Bakos, Aziz, & Rowland, 2005). Although this sample drawn from four Ontario centers included a diverse group of parents, their needs were remarkably similar. No clear trends emerged based on severity of hearing loss, type of sensory device, or route to identification. It was noteworthy that the needs described by the two different groups of families, screened and unscreened, were very comparable. The only notable difference was in the early diagnostic period where families of children diagnosed in the absence of a screening program described the need for easier access and/or a smoother transition to pediatric audiology and therapy services (Fitzpatrick, Graham, et al., 2007). The current newborn hearing services strive to offer common core components at the diagnosis and early management stages, with intervention programs adapted to the various regions of the province (Hyde et al., 2004).

At the time of the interviews, there were clearly major differences among centers on how they approach and coordinate care; however, these interviews suggested that no one model is necessarily ideal for all families. As research in other fields has demonstrated, patients’ views on appropriate health care appear to be largely affected by that which is familiar to them (Porter & Macintyre, 1984). However, there are clearly several important attributes of services from the perspectives of families across the system, namely, high-quality therapy and audiology services, well-coordinated care with communication between involved professionals, and ongoing easy access to up-to-date information. In summary, this study demonstrated that although parents are typically satisfied with the quality of intervention services, certain gaps in how the diagnostic information is delivered, how parents locate services and resources, and access to ongoing information need to be addressed in implementing pediatric hearing care programs that meet consumer preferences. Services that meet parents’ preferences may better engage families in the care process and therefore lead to better developmental outcomes (Calderon, 2000; Moeller, 2000).

The findings complement and expand on previous work by illuminating more specifically the needs and preferences of parents of very recently diagnosed children. Our findings related to information needs are consistent with previous research that has addressed the question of families’ wishes after identification of hearing loss (Luterman & Kurtzer-White, 1999; Minchom, Shepherd, White, Hill, & Lund, 2003; Roush, 2000). While parents in our study welcomed information about various communication options (e.g., oral and signing programs), in contrast to previous reports, this did not emerge as an important theme in the interviews (DesGeorges, 2003; Roush, 2000). This may be because the information was readily available or, as stated by some parents, because the decision about choosing an oral communication option was clear from the time of diagnosis. In our research, parents were most concerned with receiving guidance on how to access the various oral programs that were available. Our findings also differed from studies emanating from the United States, where the physician or medical home plays a role in managing the child with hearing loss (Gravel & McCaughey, 2004). There was little discussion of physician involvement for screened children and little involvement beyond the initial referral phase for those families whose children were identified through traditional referral routes. This may simply reflect a difference in how services are organized in the two countries, with audiology and therapy responsible for management of the child with hearing loss separately from primary health care.

In our research, parents’ views on the initial diagnostic period are consistent with recent qualitative research findings in the United Kingdom in which professional manner and communication emerged as a significant predictor of experience during the diagnostic process (Tattersall & Young, 2006). In our study, although there was a high level of satisfaction with audiology services, the initial delivery of information also emerged as a weakness in the system for some families. A broad overview of parents’ service needs over time has received limited attention in pediatric hearing despite the current emphasis on patient perceptions in health care and on involving patients in the evaluation of health care interventions. A comprehensive study on parents’ views of service provision conducted in 1999 in the United Kingdom in preparation for newborn hearing screening services found that parents valued coordinated services, access to parent support groups, and family-centered care (Robinshaw & Evans, 2003). To our knowledge, our study is the first in the Canadian context to examine parents’ perceptions of service provision and specifically the perceptions of parents who have selected oral communication development.

A strength of our study is that 17 families from four different clinical programs in the province of Ontario participated, and therefore the themes reflect a collective experience rather than that of any one service model. However, all but 2 participants were drawn from primarily urban areas, so the perspectives of rural families have received less attention. Likewise, the views of families from lower socioeconomic levels may not be well reflected. Although we made an effort to purposefully select families with diverse characteristics, these families are typical of those who voluntarily participated in this series of studies in our program, and they represent primarily a well-educated group of parents who are involved in their child’s rehabilitation program. However, the study findings are based on a varied sample of parents of children who differed in severity of hearing loss, types of hearing devices, route to diagnosis, and time since diagnosis. Considerable details and description have been provided so that the reader can decide whether these findings are transferable.
to other settings. The study results are based on rigorous qualitative techniques whereby one interviewer ensured consistency in data collection. Threats to validity were minimized through regular meetings with an interdisciplinary committee, rigorous data collection, audio-taping and verification of the concepts by a second reviewer.

This study is a starting point for several other important questions related to service models for children and families affected by hearing loss. Through the discussions with families, we endeavored to capture the important characteristics of service models but did not attempt to quantify the relative importance of the various attributes. While factors such as age of identification and severity of hearing loss have been shown to affect communication outcomes, the extent to which health services act as a determinant of outcome requires further investigation. The findings from this study have informed the development of a conjoint analysis survey to quantify parents’ preferences for the various attributes of service (Fitzpatrick, Coyle, et al., 2007). In addition, the needs of families who reside outside major regional centers require further examination. Also, this study was conducted within 3 to 4 years after the implementation of a province-wide universal neonatal screening program. As the provincial newborn hearing screening program matures, further research should evaluate whether some of the problems encountered by families, particularly with respect to the lack of coordinated services, have been resolved. Given the proliferation of early detection and intervention programs, continuing research using a variety of methodological approaches to better understand parents’ needs in order to tailor and evaluate programs is of utmost importance. Further approaches should focus on how to implement care models with the active involvement of patients.

Early detection of hearing loss accompanied by optimal intervention services may reduce or even prevent delayed development. The results of this study highlight the value of eliciting parents’ perspectives on support services that affect their child and family. Parents’ views of appropriate services may have a strong influence on their willingness and ability to be involved in their child’s care as well as in decision making at various times during the care process. The findings from our research can be used in optimizing models of care for children and families, ensuring that parents’ perspectives are taken into account throughout the continuum of care. Because effective communication is known to be associated with optimal health outcomes, understanding what, when, and how information should be delivered to patients becomes vital to ensuring the delivery of appropriate care. Such knowledge can help tailor programs and services to achieving more effective communication and patient decision making and perhaps ultimately improved outcomes for children with hearing loss and their families.

This study provides an awareness of parents’ needs from their perspectives and their description of current strengths and gaps in the system. From a policy perspective, an understanding of how parents value the components of service delivery can provide insights into the most valued services for families. There has been little attention in the literature on models of service delivery and their impact on child outcomes and parents’ motivation and ability to follow treatment programs. Although screening methods are highly prescriptive and protocol-oriented, best practices for intervention services following identification of hearing loss have not been well defined. One goal of a well-implemented hearing screening program is to offer a coordinated system of care (Hyde, 2005). This study could be used as a starting point in informing the development of quality indicators for program evaluation.

In summary, this study contributes to the growing evidence base in pediatric hearing health care privileging the consumers’ voice—families of children with hearing loss. Our study adds to the understanding of parents’ perceptions of their needs in parenting and developing oral communication skills in their young children who have permanent hearing loss. By virtue of its intensive and long-term nature, service provision for young children with hearing loss involves a social contract with families that must be recognized and given priority. Parents want to be recognized as active partners in providing the optimal system of care for their child. These findings support the need to include parents in decision making about designing programs. Early detection through population screening alone may not be sufficient to improve outcomes unless practices are in place to support and guide parents in facilitating their child’s language development. Further understanding of parents’ needs may improve the delivery of childhood hearing services and maximize the investment in newborn hearing screening.

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